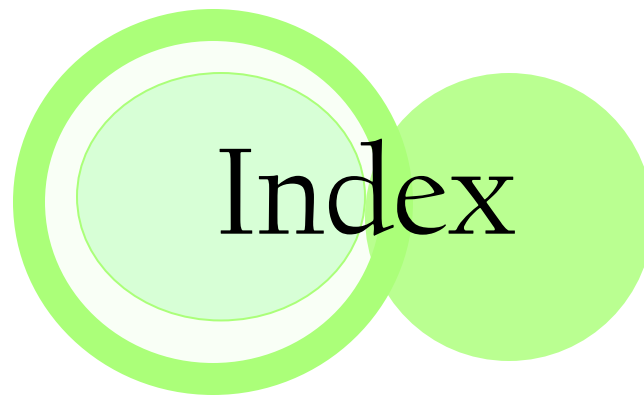




My Personal Health Record



Index

This personal health record is a place for me to organize all the information and paperwork I get from the many healthcare professionals I see. When I am an adult this health record will also allow me to look back on all of my health history.

Here are all the sections in this Personal Health Record:

- About Me
- Medical Guidelines
 - How Big I am
 - Immunizations
 - Medications
- Lab Test Results
 - Pediatrician
 - Cardiologist
 - Audiologist
 - ENT Doctor
- Ophthalmologist
- Speech Language Pathologist
- Other Healthcare Professionals
- Other Important Documents
 - Education
 - Contracts
 - Business Cards
 - Extra Copies
 - Adulthood

If you run out of space, just photocopy a new page from the “extras” section and add it to the binder.

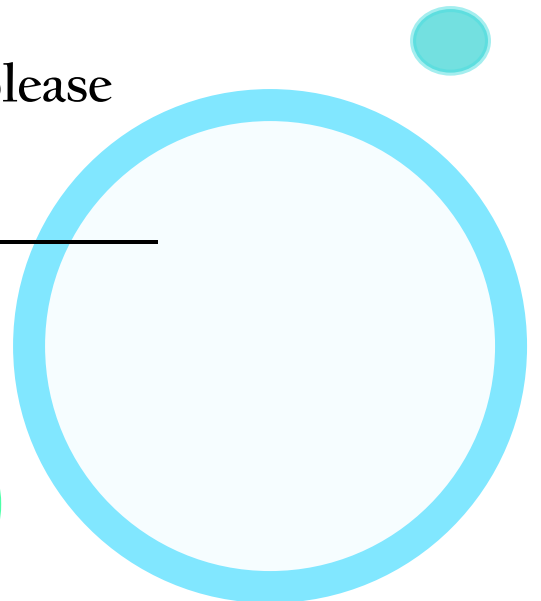
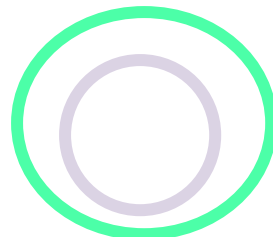
About Me

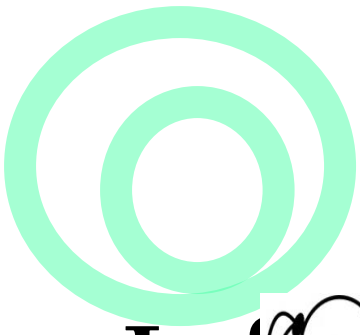
My Name Is:

My Birthday Is:

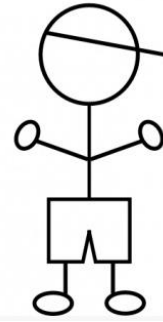
Alberta Health Care Number:

If this record is found please
contact:





Important Information About Me



My Allergies and Reactions:

My Diagnoses (What I have):

My Past Surgeries:

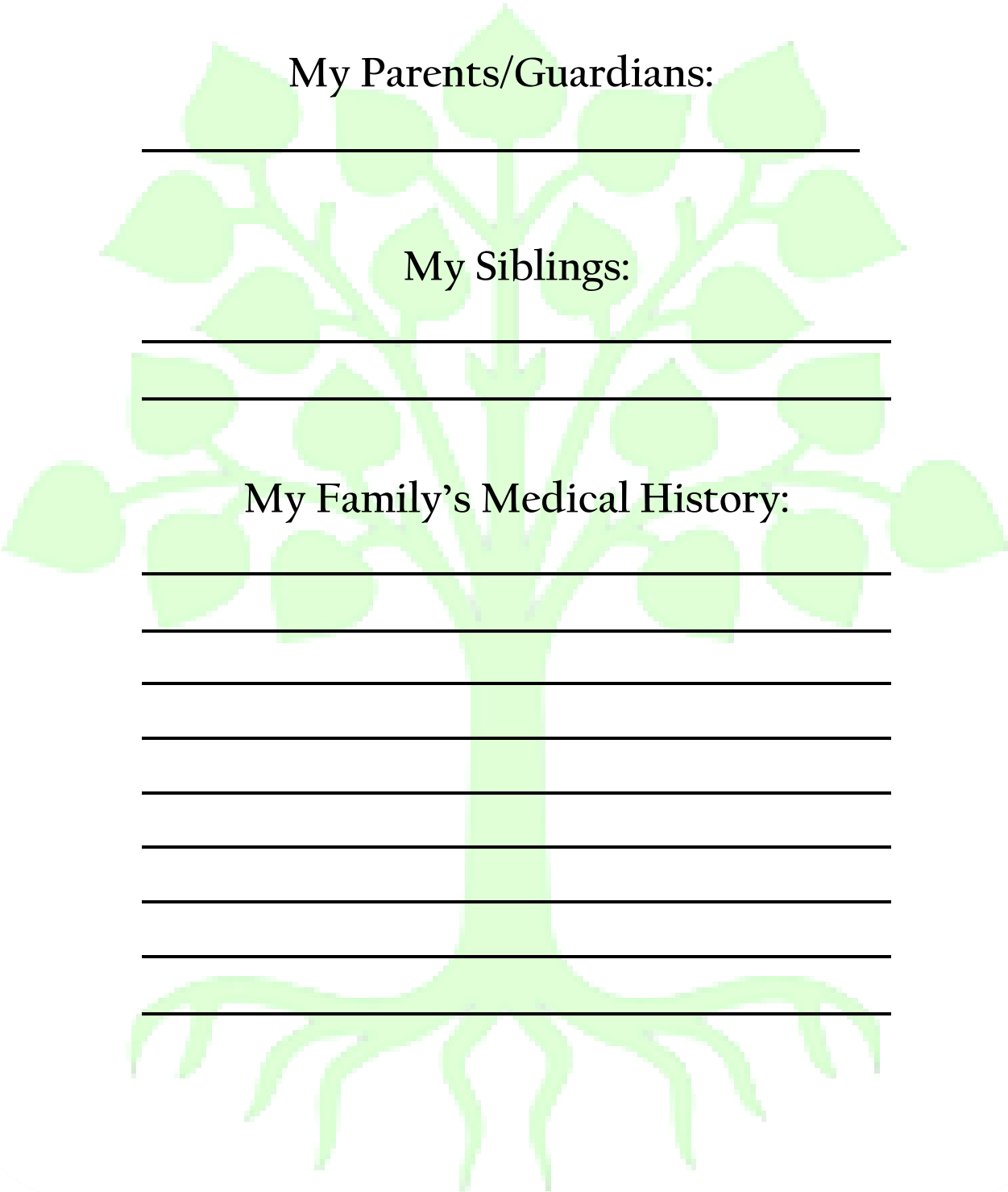
My Past Hospital Stays:

My Family

My Parents/Guardians:

My Siblings:

My Family's Medical History:



People in My Life

Pediatrician (Kid's Doctor)

Name:

Phone #:

Fax #:

Address:

Dentist (Teeth)

Name:

Phone #:

Fax #:

Address:

Cardiologist (Heart)

Name:

Phone #:

Fax #:

Address:

Ophthalmologist (Eyes)

Name:

Phone #:

Fax #:

Address:



Audiologist (Ears)

Name:

Phone #:

Fax #:

Address:

ENT Doctor (Ears, Nose, Throat)

Name:

Phone #:

Fax #:

Address:

Speech Language Pathologist
(Speech)

Name:

Phone #:

Fax #:

Address:

Name:

Phone #:

Fax #:

Address:



Name:

Phone #:

Fax #:

Address:

Name:

Phone #:

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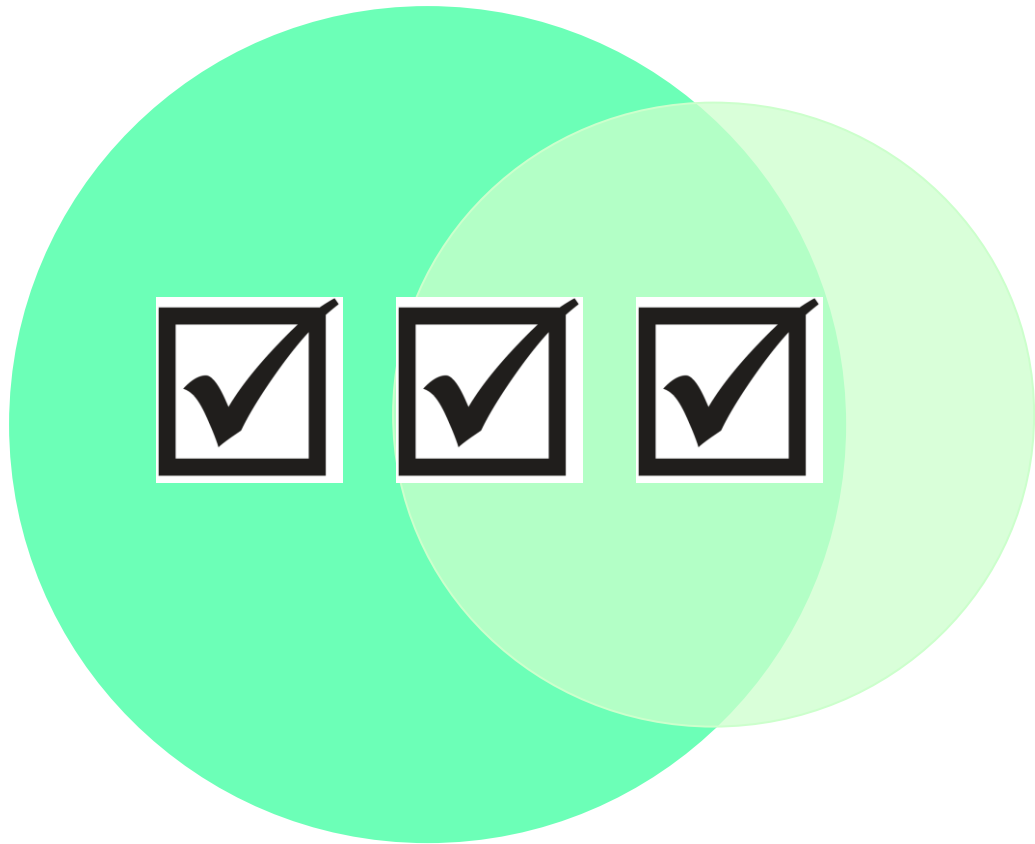
Name:

Phone #:

Fax #:

Address:

Medical Guidelines





Clinical Guidelines for the Down Syndrome population

Neonatal (birth -1 month)

History:

- Review parental concerns.
- Was there a prenatal diagnosis of DS?
- With vomiting or absence of stools, check for gastrointestinal tract blockage (duodenal web or atresia, or Hirschsprung disease);
- review feeding history to ensure adequate caloric intake;
- Any concerns about hearing or vision? Inquire about family support.

Exam:

- Pay special attention to cardiac examination;
- Cataracts (refer immediately to an ophthalmologist if the red reflex is not seen);
- Assess ear canals- can you visualize tympanic membranes (smaller in this population)
- Fontanelles may be larger with a sagittal fontanelle gap from anterior to posterior fontanelle.
- Exam for plethora, petechiae (thrombocytopenia).

Lab and Consults:

- Chromosomal karyotype; genetic counseling;
- Hematocrit or complete blood count to investigate plethora (polycythemia) or thrombocytopenia (possible myeloproliferative disorders);
- Thyroid function test - check on results of provincial neonatal screening;
- Evaluation by a pediatric cardiologist including echocardiogram (even in the absence of a murmur);
- Reinforce the need for subacute bacterial endocarditis (SBE) prophylaxis in susceptible children with cardiac disease; ** new guidelines attached**
- Refer for auditory brainstem response (ABR) or oto-acoustic emission (OAE) test to assess congenital sensorineural hearing at birth or by 3 months of age.
- Refer for a pediatric ophthalmologic evaluation by six months of age for screening purposes. Refer immediately if there are any indications of nystagmus, strabismus, absent reflexes or poor vision.
- If feeding difficulties are noted, consultation with feeding specialist (occupational therapist or lactation consultant) is advised.
- RSV vaccine for first year of life all kids with Ds qualify

Developmental:

- Discuss value of Early Intervention (infant stimulation) and refer for enrollment in local program. This is an opportunity to discuss the unfolding nature of their child's development, the importance of developmental programming, and an expectation of being able to answer that question closer to two years of age.

Recommendations:

- Referral to local Down syndrome parent group for family support, as indicated.
- Homecare and early intervention referrals as well.
- Discuss child tax credit
- FSCD(family support for children with disabilities)



Infancy (1 - 12 months)

History:

- Review parental concerns.
- Question about respiratory infections (especially otitis media);
- For constipation, use aggressive dietary management and consider Hirschsprung disease if resistant to dietary changes and stool softeners (passing of large stools clinically rules out Hirschsprung disease).
- Solicit parental concerns regarding vision and hearing.

Exam:

- General neurological,
- Neuromotor, and musculoskeletal examination;
- If unable to visualize tympanic membranes refer to ear, nose and throat (ENT) specialist,

Lab and Consults:

- Evaluation by a pediatric cardiologist including echocardiogram (if not done in newborn period): remember to consider progressive pulmonary hypertension in Down syndrome patients with a VSD or atrioventricular septal defect who are having little or no symptoms of heart failure in this age group.
- Auditory brainstem response test (ABR) by 3 months of age if not performed previously or if previous results are suspicious.
- Pediatric ophthalmology evaluation by six months of age (earlier if nystagmus, absent reflex, strabismus or indications of poor vision is present).
- Thyroid function test (TSH and T4), at 6 and 12 months of age.
- Evaluation by ENT specialist for recurrent otitis media as needed.
- Qualify in Alberta for RSV vaccine with DS < 1 year.

Developmental:

- Discuss early intervention and refer for enrollment in local program (if not done during the neonatal period). This usually includes physical and occupational therapy evaluations and a developmental assessment.
- SLP services initiated here
- Child tax credit forms, FSCD plan (will require physician letter regarding private SLP services)

Recommendations:

- Continue family support
- Continue SBE prophylaxis for children with cardiac defects. ** guidelines attached**
- Immunization according to routine schedule, including influenza, children under one year are eligible for RSV prophylaxis ** updated criteria attached**



Childhood (1 year to 12 years)

History:

- Review parental concerns
- current level of functioning
- review current programming (early intervention, preschool, school)
- ear problems
- sleep problems (snoring or restless sleep might indicate obstructive sleep apnea)
- constipation
- assess for signs of hearing loss
- thyroid function tests
- review ophthalmologic and dental care
- Monitor for behavior problems
- Review signs and symptoms of obstructive sleep apnea (Snoring, apnea, restless sleep)
- Review any symptoms of joint disease- OA, JA , gouty arthritis(increased uric acid)- these are more common in individuals with Down syndrome

Exam:

- General pediatric and neurological exam
 - Including evaluation for signs of spinal cord compression: deep tendon reflexes, gait, Babinski sign.
 - Include a brief vulvar exam for girls.
- Use Down syndrome growth charts, as well as growth charts for typically developing children. Be sure to plot height for weight on the latter chart.
- Be Aware of Celiac prevalence 4-17 %-**one time** screening of whole population without symptoms (age 3). Screen for symptoms: disordered bowel function tending to diarrhea or new onset constipation, failure to thrive using DS growth charts, abdominal distention, general unhappiness and misery, arthritis, rash suggestive of Dermatitis herpetiformis, type I diabetes, thyroid disease or anemia.
 - If Antitransglutaminase positive, IgA pos and signs and symptoms, or immunologically negative with significant symptoms proceed to small intestinal biopsy.
 - treat with gluten free diet

Lab and Consults:

- Echocardiogram by a pediatric cardiologist if not done previously;
- Thyroid function test (TSH and T4) yearly;
- Screen as above for Celiac as above at age three (as per NASPGHN guidelines), on subsequent visits screen with any clinical suspicion.
- Behavioral auditory testing every 6 months until 3 years of age, then yearly.
- Continue regular eye exams every year if normal, or more frequently as indicated.** guidelines attached**
- Initial dental evaluation at two years of age with follow-ups every six months. Administer immunizations as per Canadian guidelines.

Developmental:

- Enrollment in appropriate developmental or educational program; complete educational assessment yearly, or Individualized
- Educational Plan (IPP) from age four until the end of formal schooling.
- Evaluation by a speech and language pathologist is strongly recommended to maximize language development and verbal communication.
- An individual with significant communication deficits may be a candidate for an augmentive communication device.



- Literacy consultation strongly recommend by age 4-5 years.
- Ensure SLP services are being provided

Recommendations:

- Twice daily teeth brushing.
- Total caloric intake should be below recommended daily allowance (RDA) for children of similar height and age.
- Monitor for well-balanced, high fiber diet.
- Regular exercise and recreational programs should be established and encouraged early.
- Continue speech therapy and physical therapy as needed.
- Continue SBE prophylaxis for children with cardiac defects.
- Monitor the family's need for respite care, supportive counseling and behavior management techniques. Reinforce the importance of good self-care skills (grooming, dressing, and money handling skills).



Adolescence (12 to 18 years)

History:

- Review interval medical history
- Continue with low level of suspicion for celiac
- Questioning specifically about the possibility of obstructive airway disease and sleep apnea (restless sleep, snoring, day time fatigue)
- Check sensory functioning (vision and hearing)
- Assess for behavioral problems
- Address sexuality issues.

Exam:

- General physical and neurological examination (with reference to atlanto-axial dislocation).
- Monitor for obesity by plotting height for weight on the growth charts for typical children.
- Pelvic exam if sexually active, only Consult gynecologist experienced in working with individuals with developmental disabilities to address issues of sexuality and/or for pelvic examination for sexually active teenager.
- Perform a careful cardiac exam in adolescents, looking for evidence of valvular disease. or if symptomatic. Echocardiogram (if evidence of valvular disease on clinical exam.)

- Lab and consults: Thyroid function testing (TSH and T4) yearly.
- Hearing and vision evaluations every year.
- Cervical spine x-rays as needed **only** for Special Olympic participation
- Continue twice-yearly dental exams.
- Testicular Exam for boys as increased risk of testicular CA in this population.

Developmental:

- Psycho-educational evaluations as needed. Monitor academic performance and individual Program Plan (IPP) every two years through schools
- Monitor independent functioning.
- Continue speech/language therapy as needed.
- Health and sex education, including counseling regarding abuse prevention.
- Smoking, drug, and alcohol education.

Recommendations:

- Begin transition planning (age 16). Consider enrollment AISH, PDD
- SBE prophylaxis needed for individuals with cardiac disease.
- Continue dietary and exercise recommendations (see childhood, above).
- Discuss estate planning and custody arrangements.
- Encourage social and recreational programs with friends.
- Register for voting and selective service at age 18.
- Discuss plans for alternative long term living arrangements such as community living arrangements (CLA).
- Reinforce the importance of good self-care skills (grooming, dressing, and money handling skills).



Adults (over 18 years)

History:

- Interval medical history.
- Ask about sleep apnea symptoms.
- Monitor for loss of independence in living skills, behavioral changes and/or mental health problems.
- Symptoms of dementia (decline in function, memory loss, ataxia, seizures and incontinence of urine and/or stool). This may also represent spinal cord compression from atlanto-axial subluxation.
- Assess for signs and symptoms of hearing loss.

Exam:

- General physical and neurological examination (with reference to atlanto-axial dislocation). ** see attached recommendations**
- Monitor for obesity by plotting height for weight.
- Cardiac exam: listen for evidence of mitral valve prolapse and aortic regurgitation: confirm suspicions with echocardiogram.
- Sexually active women will need Pap smears every 1-3 years following the age of first intercourse.
- For women who are not sexually active, single-finger bimanual examination with finger-directed cytology exam. Screening pelvic ultrasound every 2-3 years for women who refuse or have inadequate follow-up bimanual examinations. This may require referral to an Adolescent Medicine practitioner or a gynecologist with experience with individuals with special needs. Otherwise, pelvic ultrasound may be considered in place of pelvic examinations.
- Breast exam yearly by physician
- Testicular exam yearly as increased risk of testicular CA in this population;

Lab and consults:

- Annual thyroid screening (TSH and T4).
- Ophthalmologic evaluation every two years (looking especially for keratoconus and cataracts).
- Cervical spine x-rays **as needed** for Special Olympic participation and/or if symptomatic.
- Continue auditory testing every two years.
- Mammography: a mammogram every other year beginning at 40, and yearly beginning at 50.
- Continue twice-yearly dental visits.
- Mental health referral for individuals with emotional and behavioral changes.

Developmental:

- Continue speech and language therapy, as indicated. For individuals with poor expressive language skills, consider referral for augmentive communication device.
- Discuss plans for further programming/vocational opportunities at age 21 or when formal schooling ends.
- Be aware that accelerated aging may affect functional abilities of adults with Down syndrome, more so than Alzheimer disease.

Recommendations:

- Discuss plans for alternative long term living arrangements
- SBE prophylaxis needed for individuals with cardiac disease.



- Continue dietary and exercise recommendations (see childhood, above).
- Discuss estate planning and custody arrangements.
- Encourage social and recreational programs with friends.
- Register for voting and selective service at age 18.
- Reinforce the importance of good self-care skills (grooming, dressing, and money handling skills). Bereavement counseling for individuals who have experienced the loss of an important person in their life, either via death or by other circumstances: sibling moves away after marriage, or goes off to college.



**Alberta Health
Services**

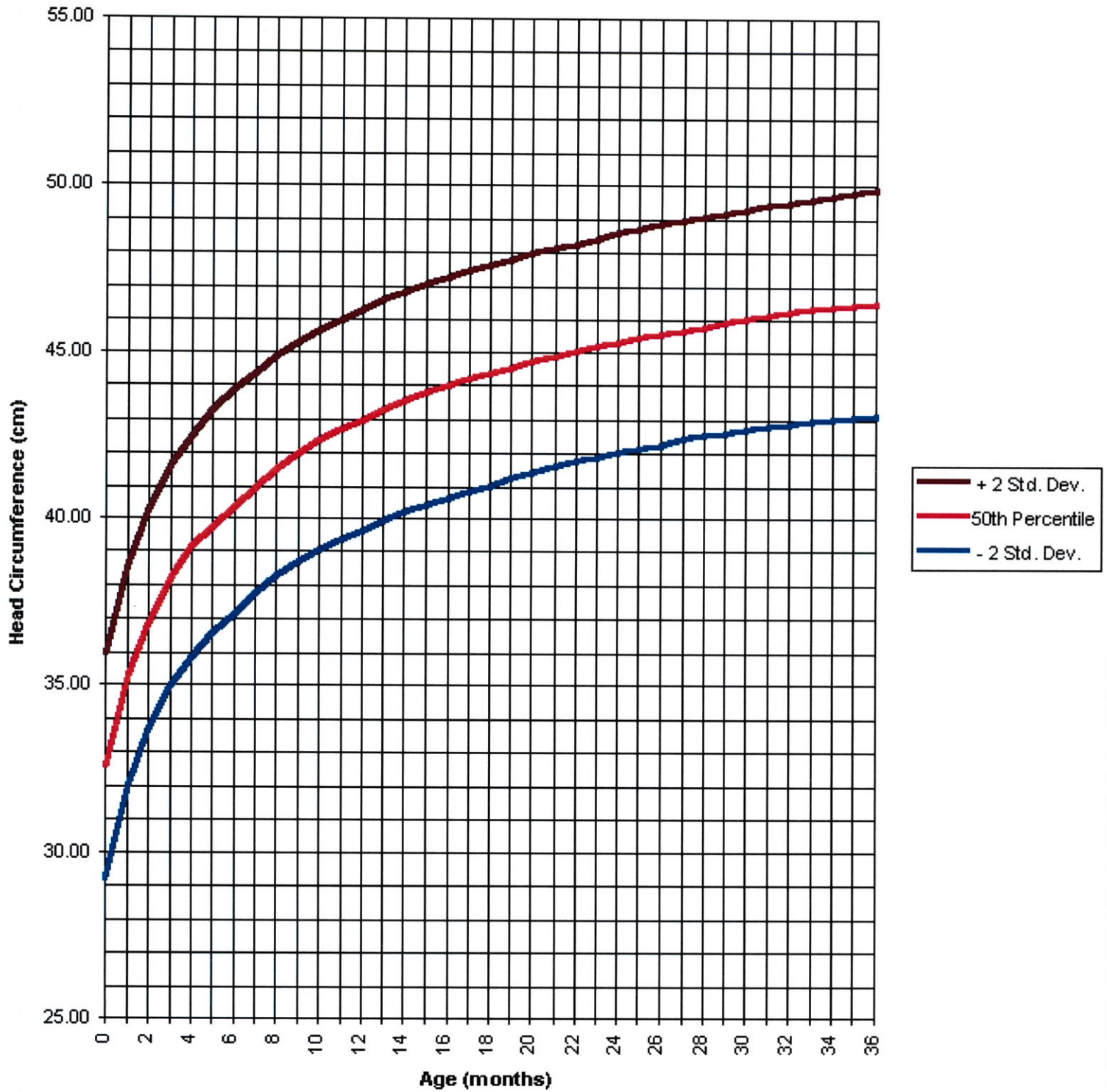


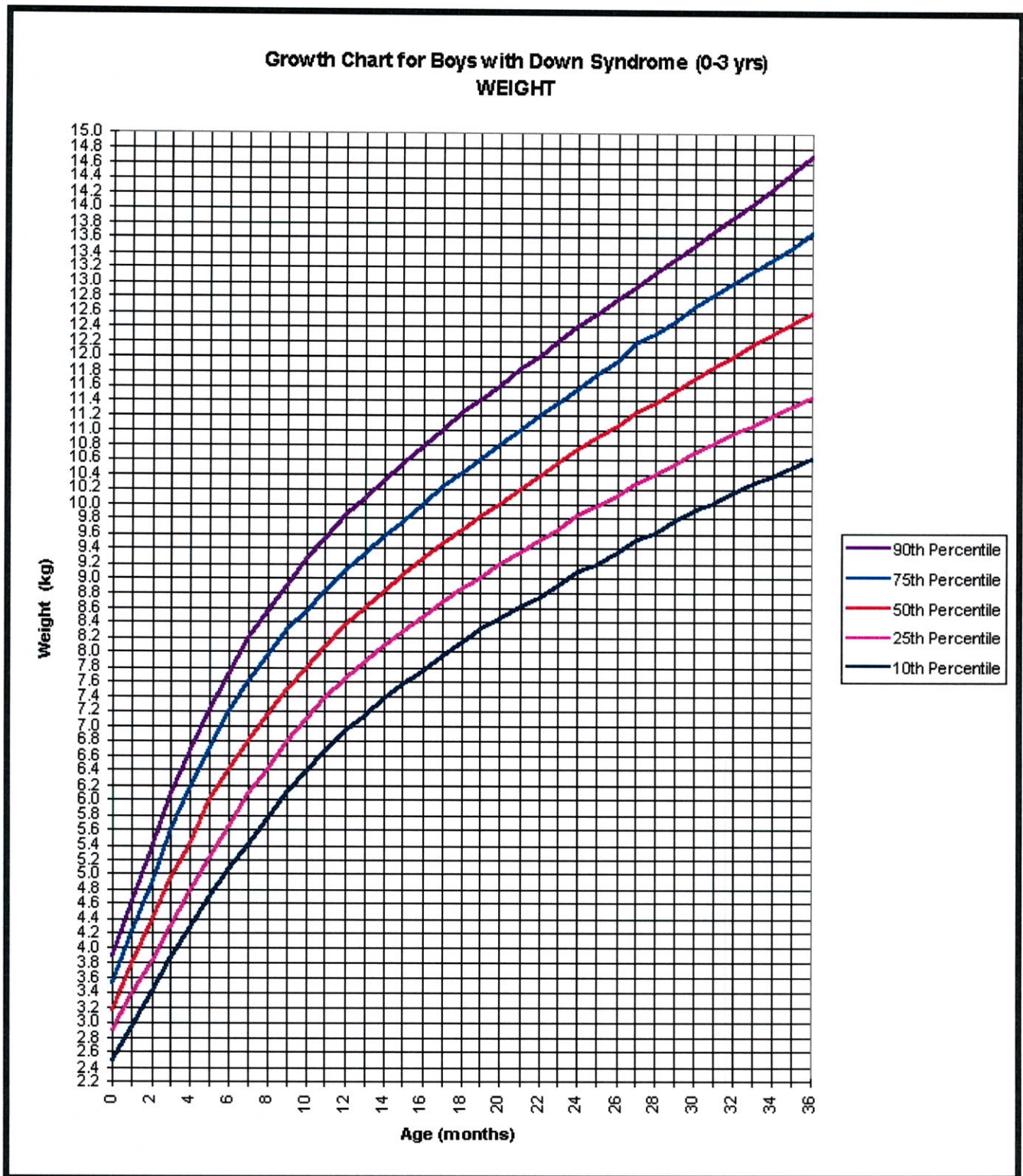
**STOLLERY
CHILDREN'S
HOSPITAL**

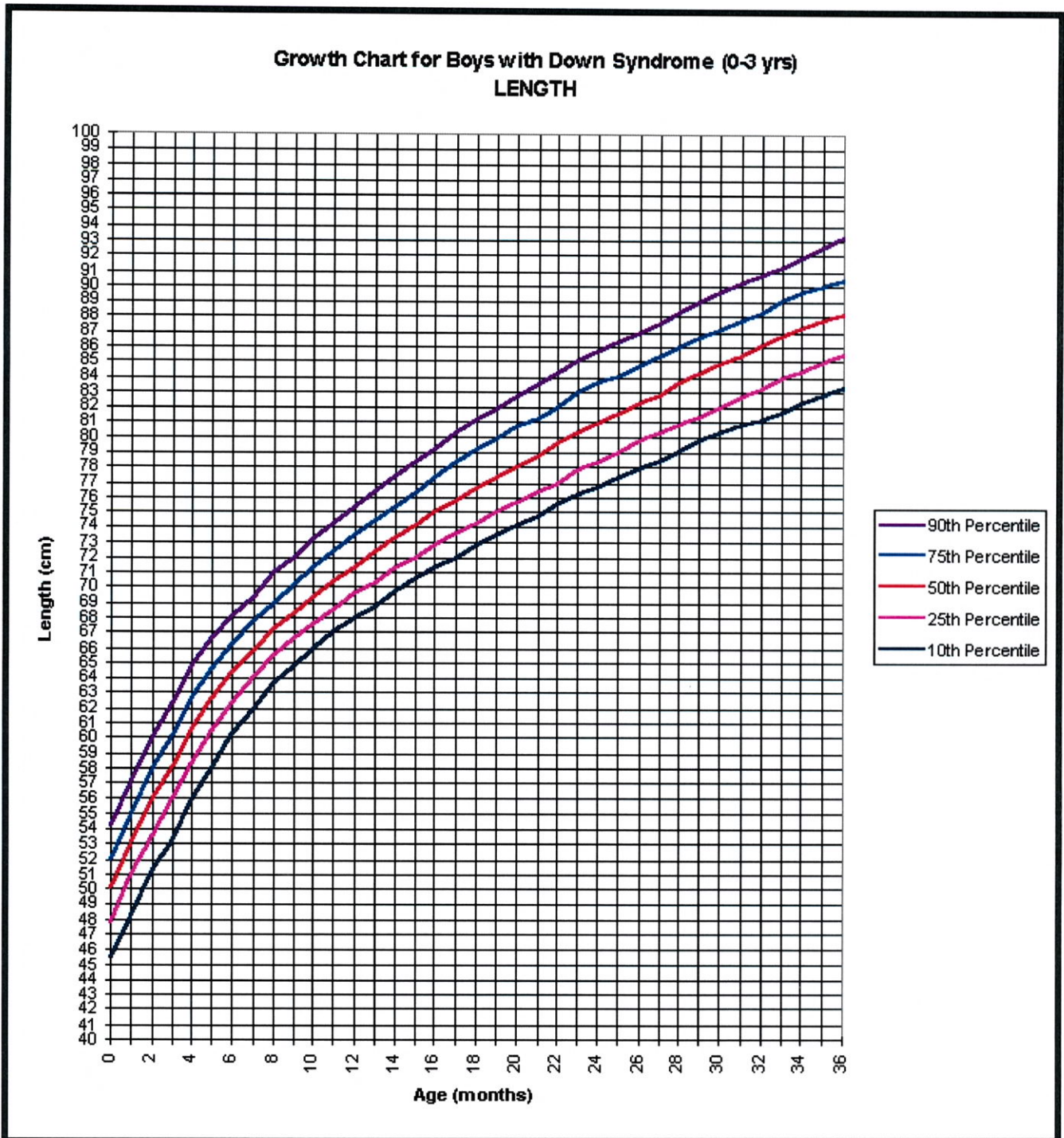


How Big I Am

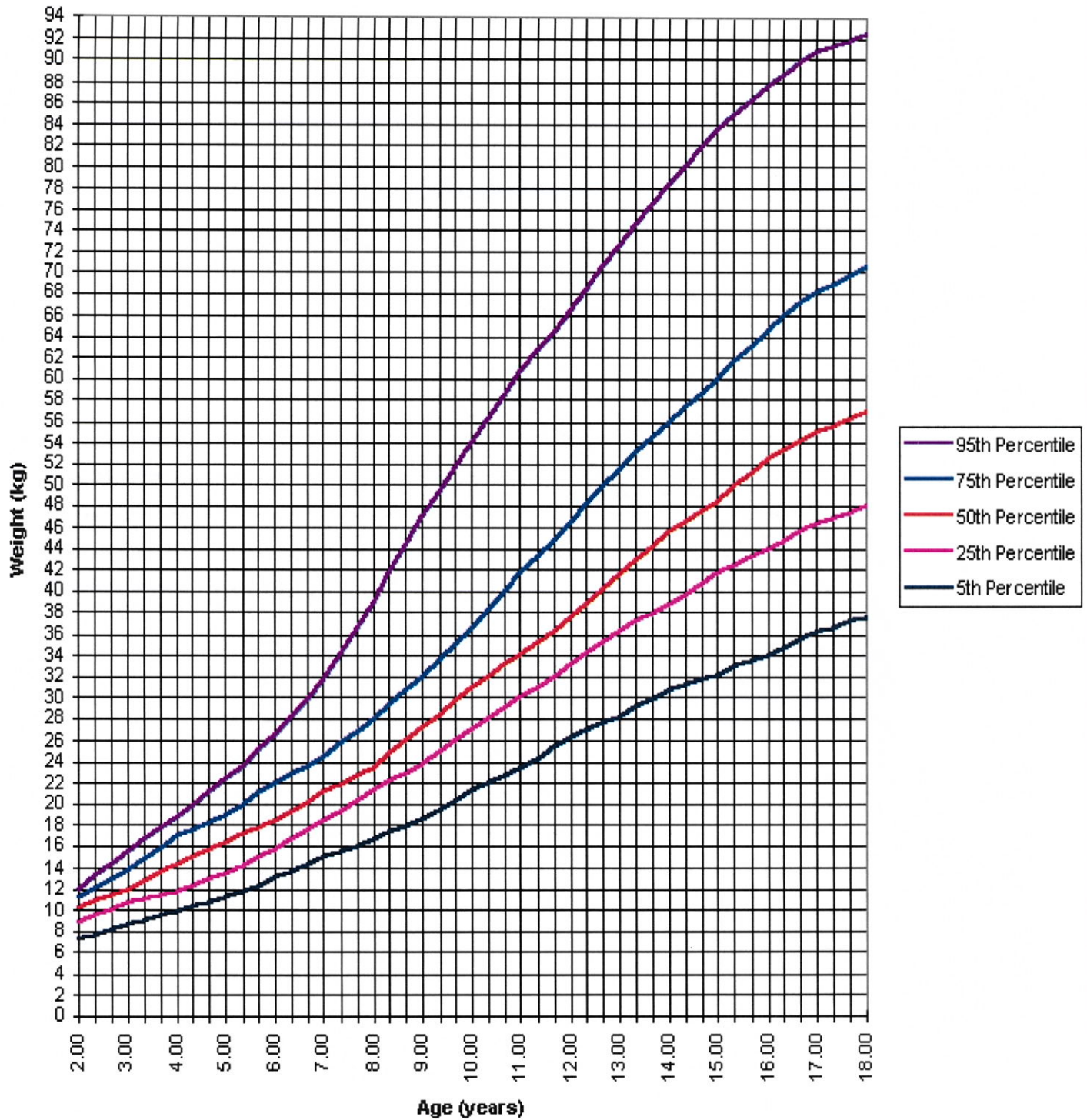
Head Circumference for Boys (0-3) w/Down Syndrome

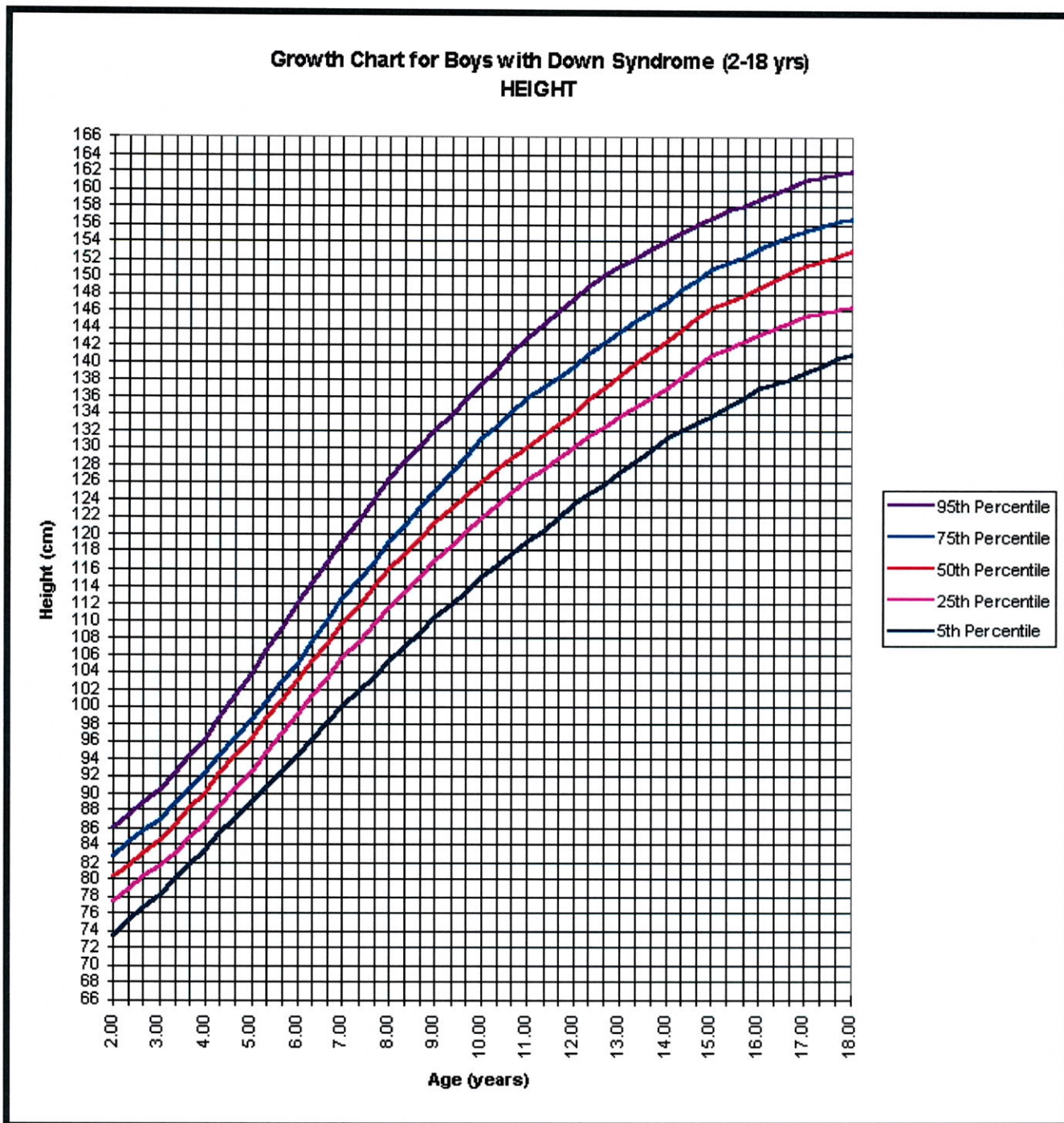


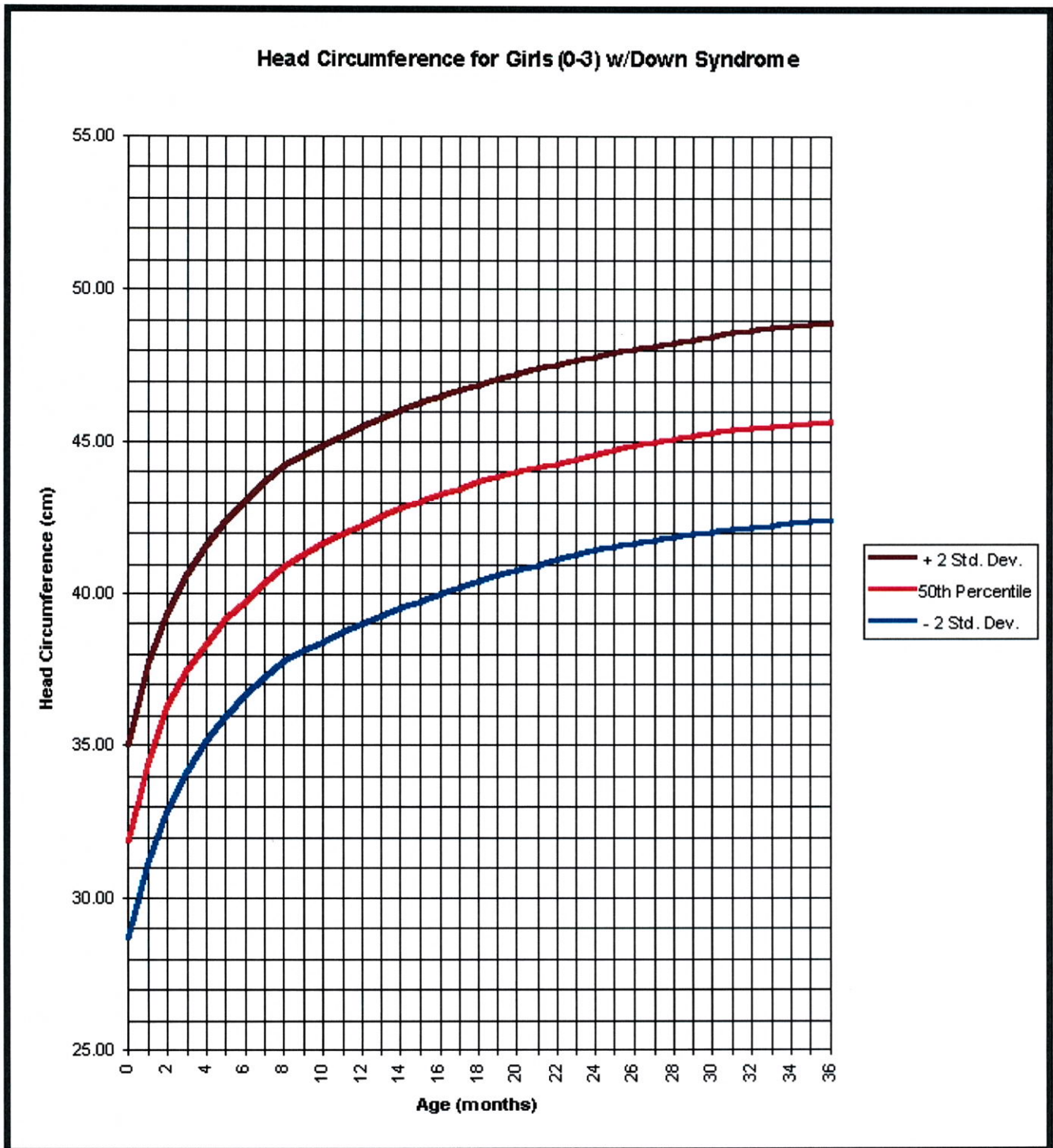


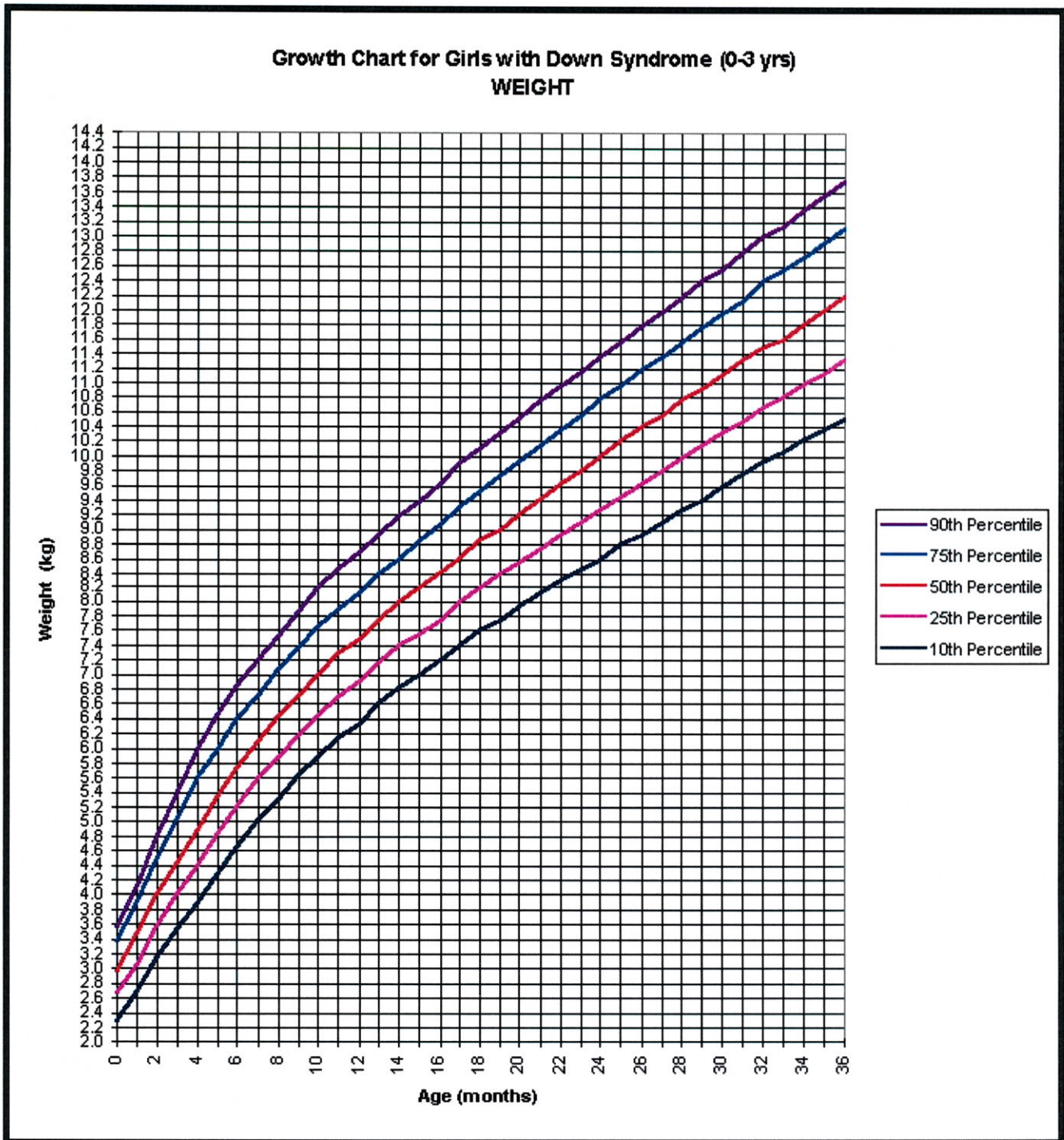


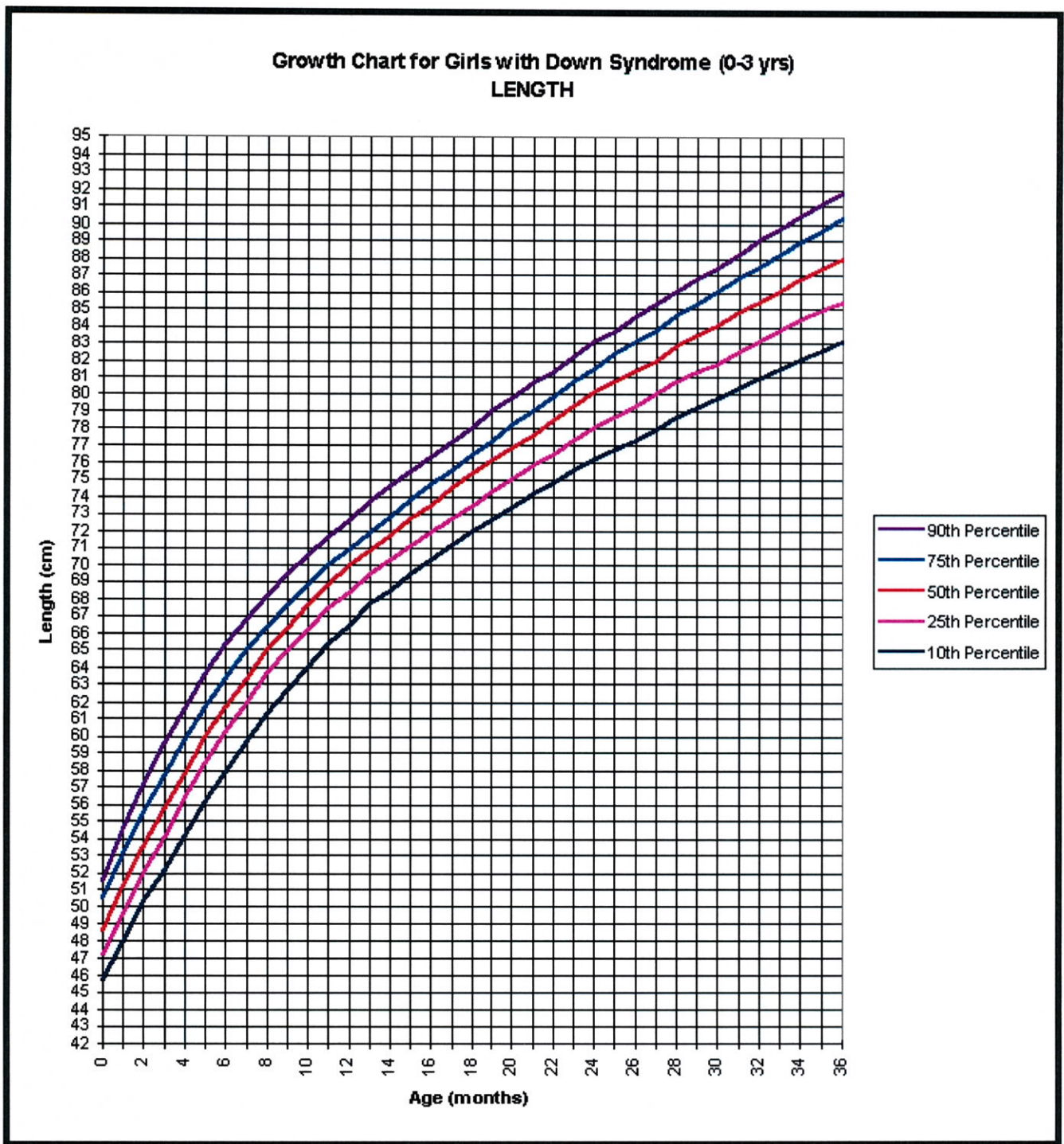
Growth Chart for Boys with Down Syndrome (2-18 yrs) WEIGHT

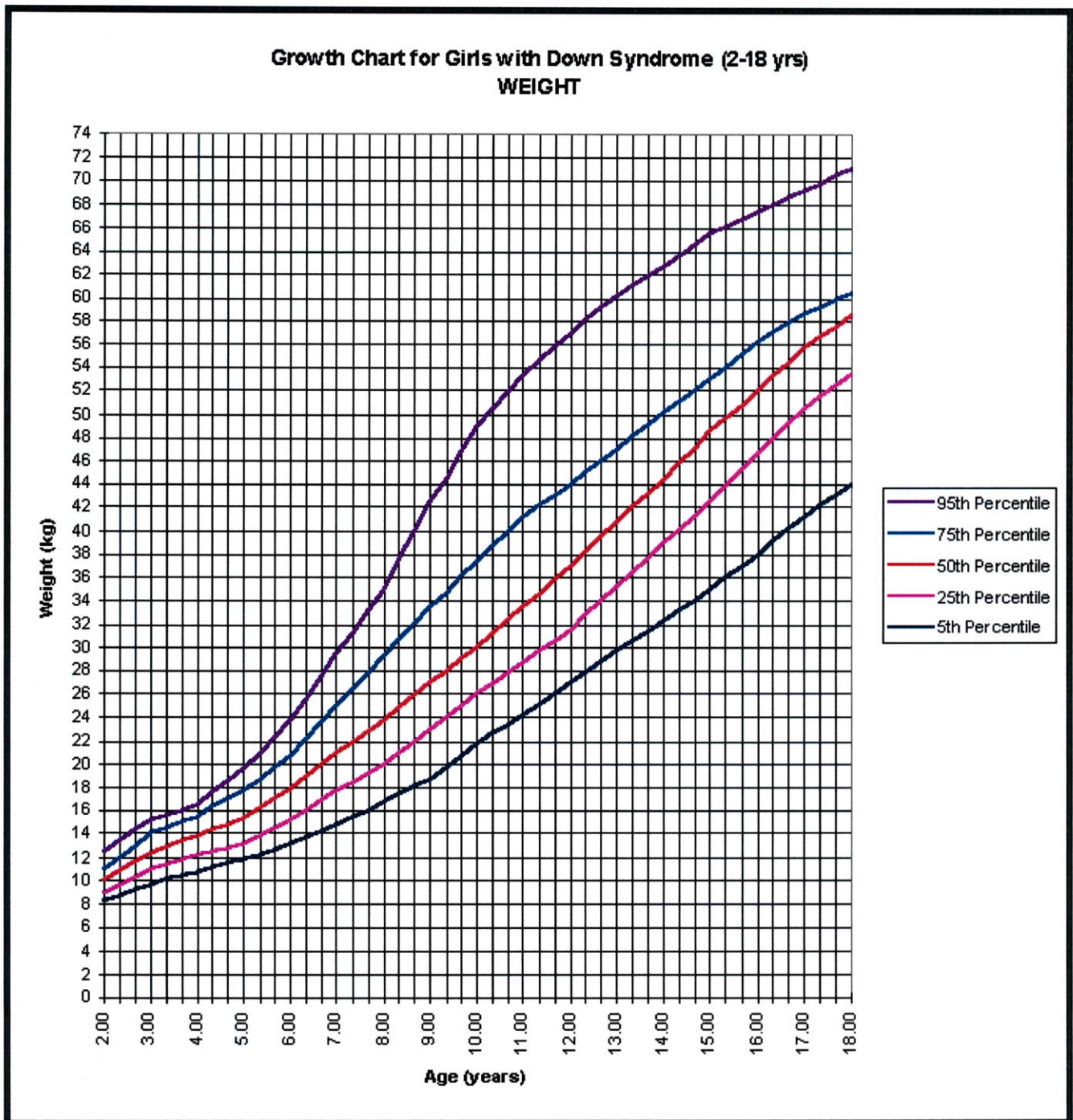






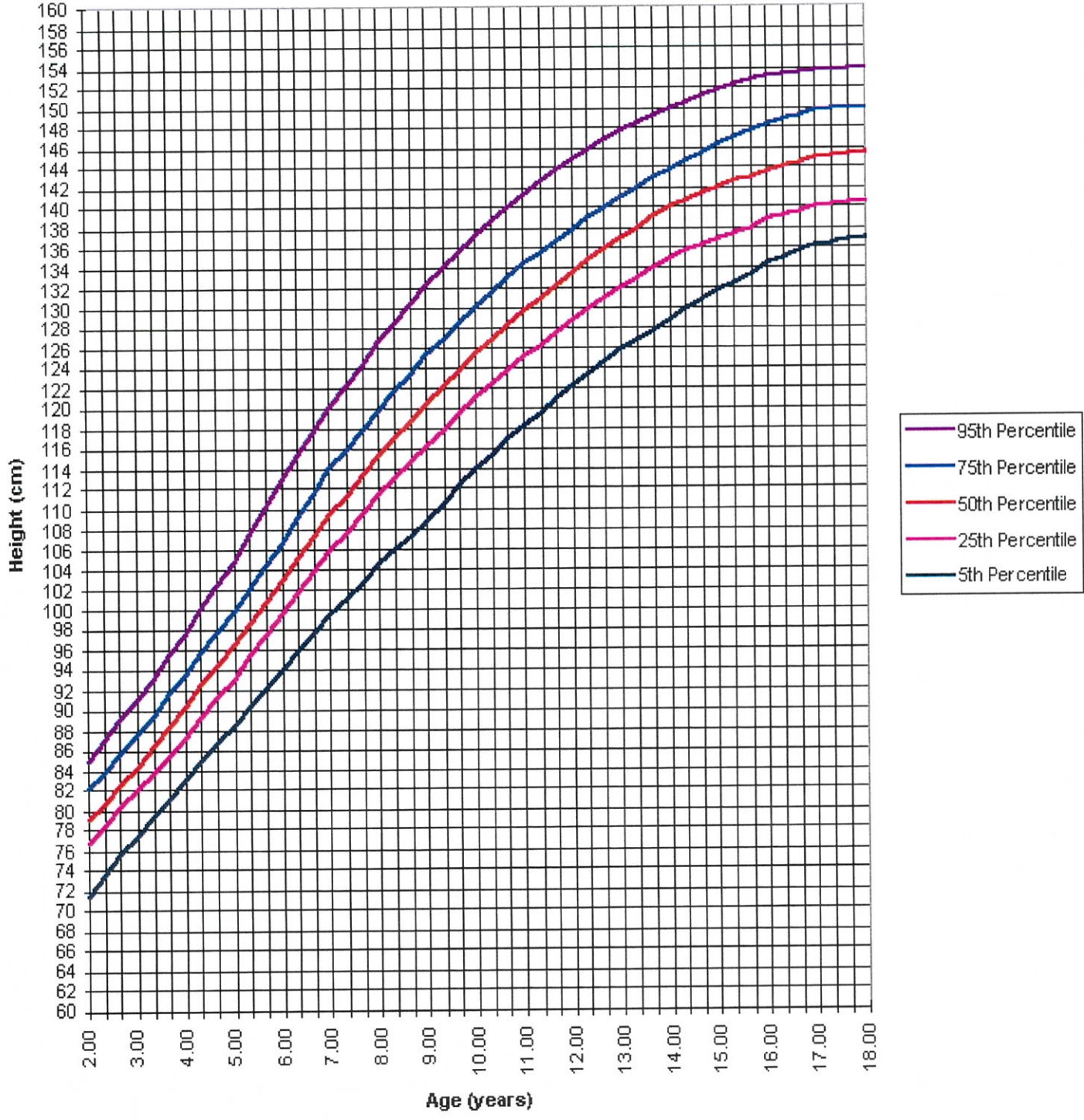






Growth Chart for Girls with Down Syndrome (2-18 yrs)

HEIGHT



Adult Weight Chart (19 years and up)

Year 				
January				
February				
March				
April				
May				
June				
July				
August				
September				
October				
November				
December				



Immunizations

Recommended Immunization Schedule

Effective: August 1, 2012

Age	Vaccine
2 months	<ul style="list-style-type: none"> • DTaP-IPV-Hib¹ • Pneumococcal conjugate (PCV13) • Meningococcal conjugate (Men C)
4 months	<ul style="list-style-type: none"> • DTaP-IPV-Hib • Pneumococcal conjugate (PCV13) • Meningococcal conjugate (Men C)
6 months	<ul style="list-style-type: none"> • DTaP-IPV-Hib • Pneumococcal conjugate (PCV13) (for high risk children only)
6 months and older	<ul style="list-style-type: none"> • Influenza²
12 months	<ul style="list-style-type: none"> • MMRV³ • Meningococcal conjugate (Men C) • Pneumococcal conjugate (PCV13)
18 months	<ul style="list-style-type: none"> • DTaP-IPV-Hib
4–6 years	<ul style="list-style-type: none"> • DTaP-IPV⁴ • MMRV³ • Pneumococcal conjugate (PCV13) only for children up to 71 months (catch up program)
Grade 5	<ul style="list-style-type: none"> • Hepatitis B (3 doses) • HPV⁵ (3 doses for females)
Grade 9	<ul style="list-style-type: none"> • dTap⁶ • MCV4⁷

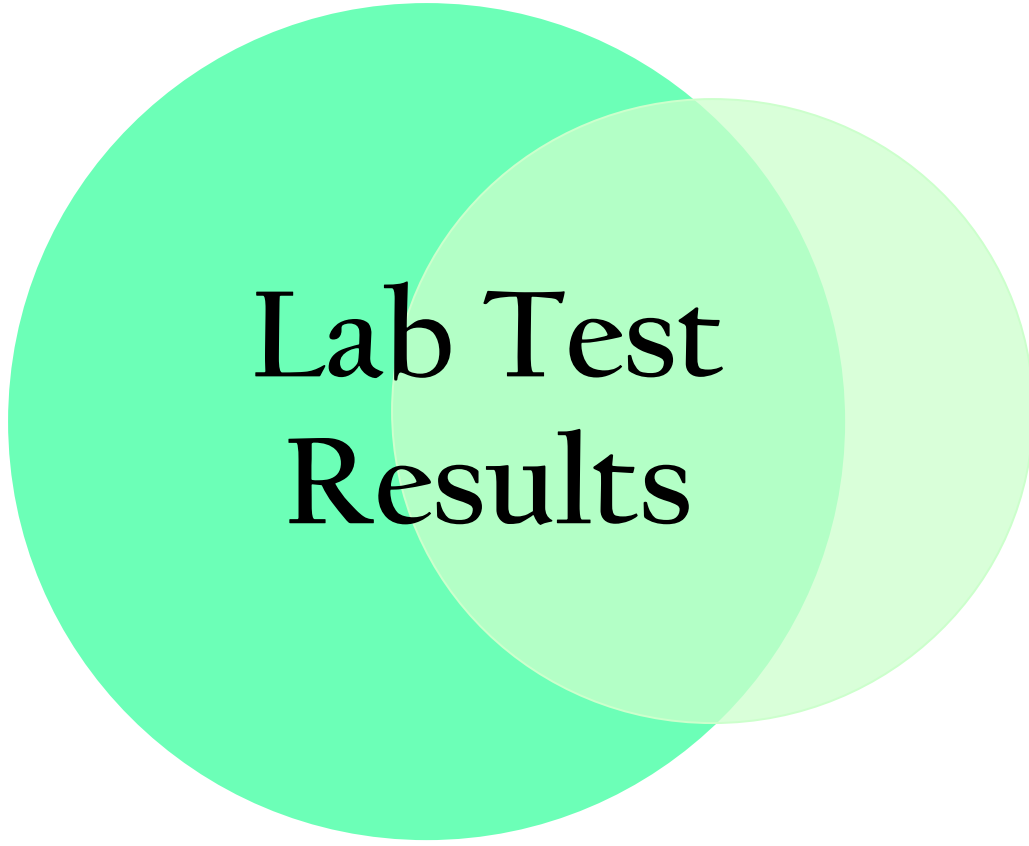
- ¹ Diphtheria, tetanus, acellular pertussis, polio, haemophilus influenzae type b
- ² Annually, during influenza season
- ³ Measles, mumps, rubella, and varicella
- ⁴ Diphtheria, tetanus, acellular pertussis, polio
- ⁵ Human papillomavirus
- ⁶ Diphtheria, tetanus, acellular pertussis
- ⁷ Meningococcal Conjugate Vaccine (Groups A, C, W-135 and Y)

(Alberta Health Services, 2012a)

The Alberta Respiratory Syncytial Virus (RSV) prevention program recommends that children with Down syndrome have the RSV vaccine within the first year of their lives (Alberta Health Services, 2012b).



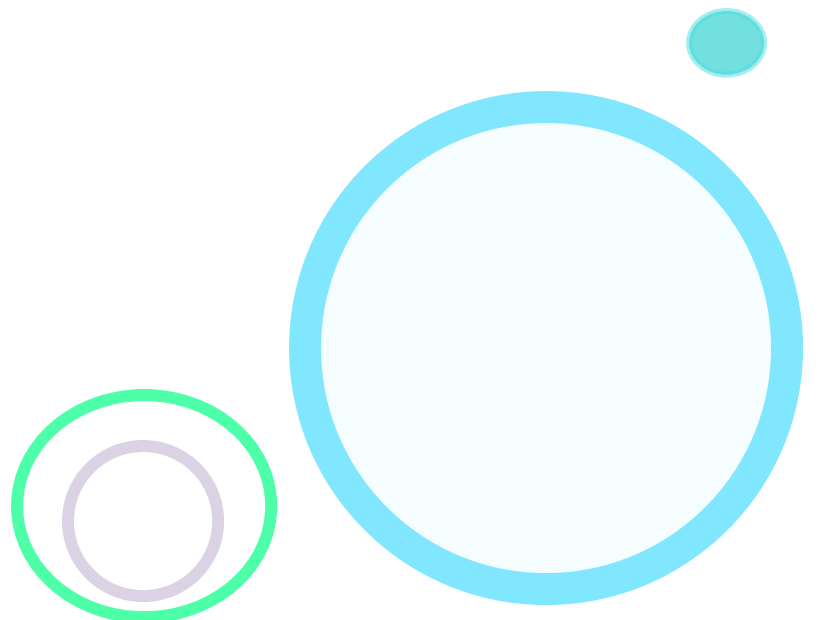
Medications

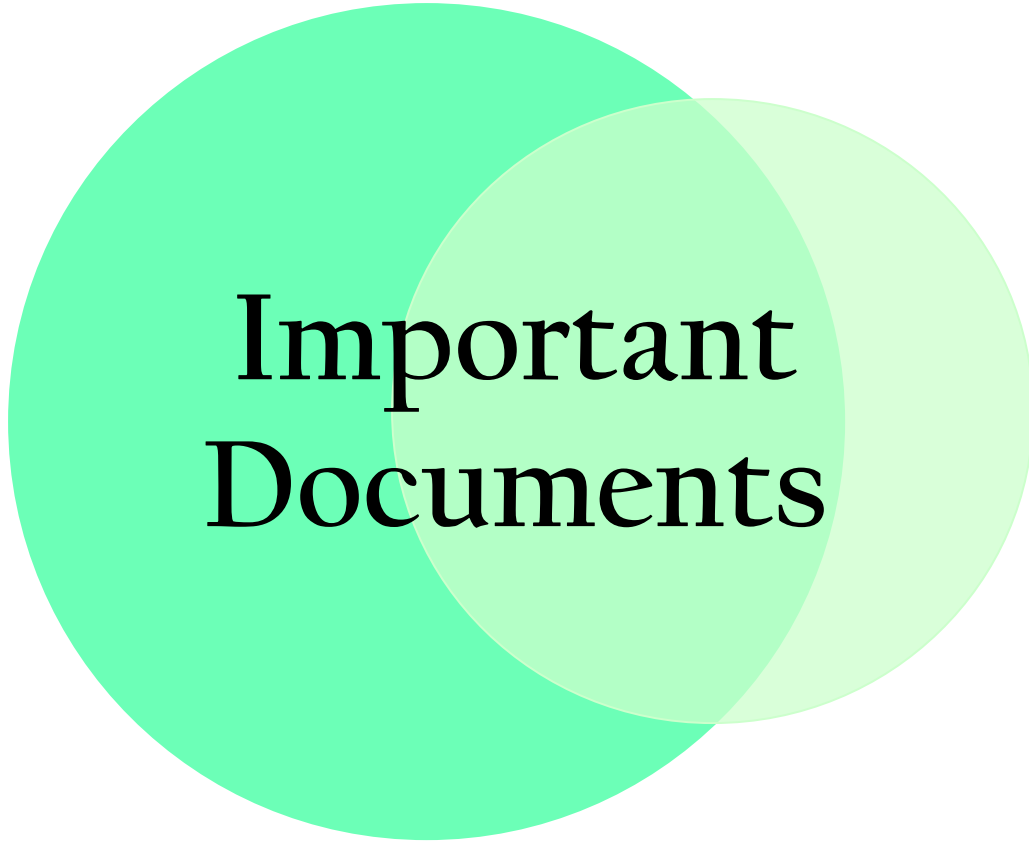


Lab Test Results

Pediatrician

A Pediatrician is a doctor who makes sure you are healthy and growing. Going to the Pediatrician also gives your parents a chance to talk with the doctor about any issues, such as safety or nutrition, so they can help you stay healthy.





**Important
Documents**

♥ THE PEDATRIC CARDIAC TEAM ♥

**IF YOU HAVE QUESTIONS OR CONCERNS,
PLEASE CALL YOUR CARDIOLOGIST OR ONE OF THE CLINIC NURSES.
FOR CARDIOLOGY CLINIC APPOINTMENTS PLEASE CALL: 780-407-3952**

**FOR URGENT CONCERNS PLEASE CALL: 780-407-8822
ASK THE SWITCHBOARD TO PAGE THE PEDIATRIC CARDIOLOGIST ON CALL.**

YOUR CHILD'S CARDIOLOGIST IS: _____

♥ **CARDIATRIC SURGEONS**

Dr. Mohammed Al-Aklabi 780-407-8033
Dr. I. Rebeyka 780-407-8033
Dr. D. Ross 780-407-8047

♥ **CARDIOLOGY CLINIC NURSES**

Pat Aldridge 780-407-3957
Lorraine Tonn 780-407-3957
Edie Ungstad 780-407-3307
Brandy Brubacher 780-407-3957

♥ **NURSE PRACTICIONERS**

Chentel Cunningham 780-407-3663
Leanne Meakins 780-407-7742

♥ **CASE COORDINATOR**

Pat Hebden 780-407-7709

♥ **DISCHARGE COORDINATOR**

Michelle Duffley 780-407-1872

♥ **SOCIAL WORKER**

Charlene Turpin 780-407-6877

♥ **PATIENT CARE MANAGER**

Jannette Hurshowy 780-407-3359

♥ **CLINICAL NURSE EDUCATOR**

Sandra Caliguri 780-407-1089

♥ **HOME CARE**

Peds Team 780-408-5960

♥ **TRANSPLANT**

Bernadette Dodd (Clinical Nurse Specialist) 780-407-7273

Kirsten Brooks (Transplant Coordinator) 780-445-7096

♥ **CARDIOLOGISTS**

Dr. J. Dyck (Director) 780-407-3964
Dr. J.Y. Coe 780-407-3963
Dr. M. Kantoch 780-407-3963
Dr. A. Mackie 780-407-8361
Dr. M. Robertson 780-407-3963
Dr. J. Rutledge 780-407-8361
Dr. J. Smallhorn 780-407-3355
Dr. E. Tham 780-407-3355
Dr. L. Hornberger 780-407-3355
Dr. I. Adatia 780-407-8361
Dr. L. West 780-492-3200

♥ **DIETITIAN**

Meghan Pohl 780-407-8143

♥ **PHARMACIST**

Nicola Devlin 780-407-7569

♥ **SPEECH – LANGUAGE PATHOLOGIST**

Reagan Cyr 780-407-8963

♥ **HOME NUTRITION PROGRAM**

Cheryl Harmata 780-407-1341

♥ **PHYSIOTHERAPY**

Susanne Bergsten 780-407-6002

♥ **CHILD LIFE**

Judy Dahl 780-407-7758

♥ **4C2/C3/C4 (UNIT MANAGERS)**

Tracy Downie 780-407-3223
Adele Benest 780-407-7427
Sheena Schendel

PEDIATRIC THROMBOSIS TEAM

CLINICAL DIRECTOR

Dr. Patricia Massicotte

NURSE PRACTITIONERS

Mary Bauman / Karina Black

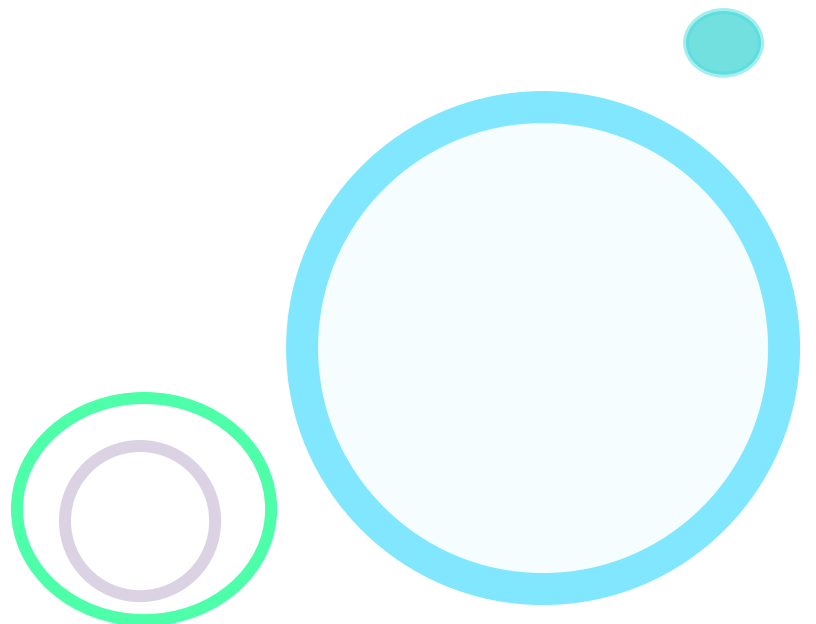
FOR THROMBOSIS CLINIC APPOINTMENTS PLEASE CALL: 780-407-1070

24 HOUR THROMBOSIS HOTLINE: 780-407-8822

ASK THE SWITCHBOARD TO PUT YOU THROUGH TO THE THROMBOSIS TEAM MEMBER ON CALL.

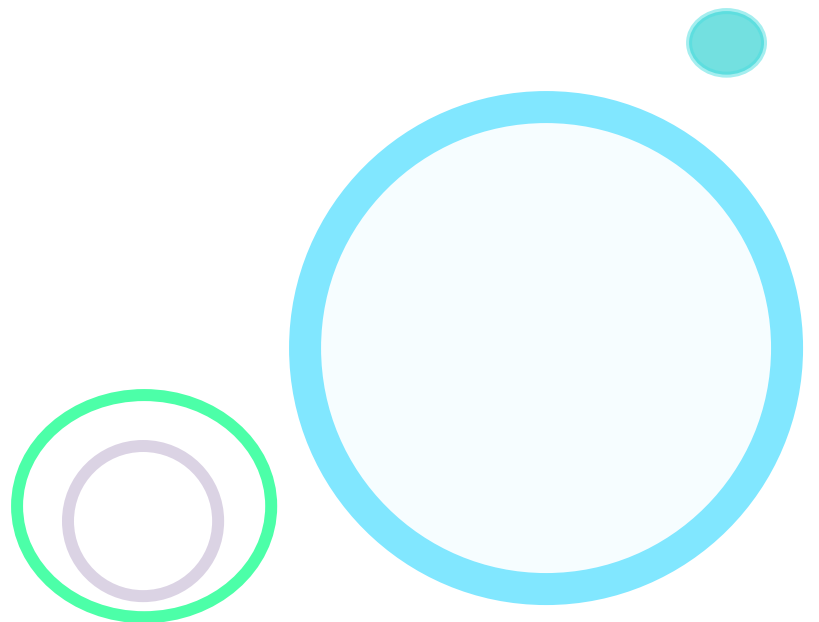
Audiologist

An Audiologist is a specialist who has been trained to understand how ears work and help people whose ears don't hear properly.



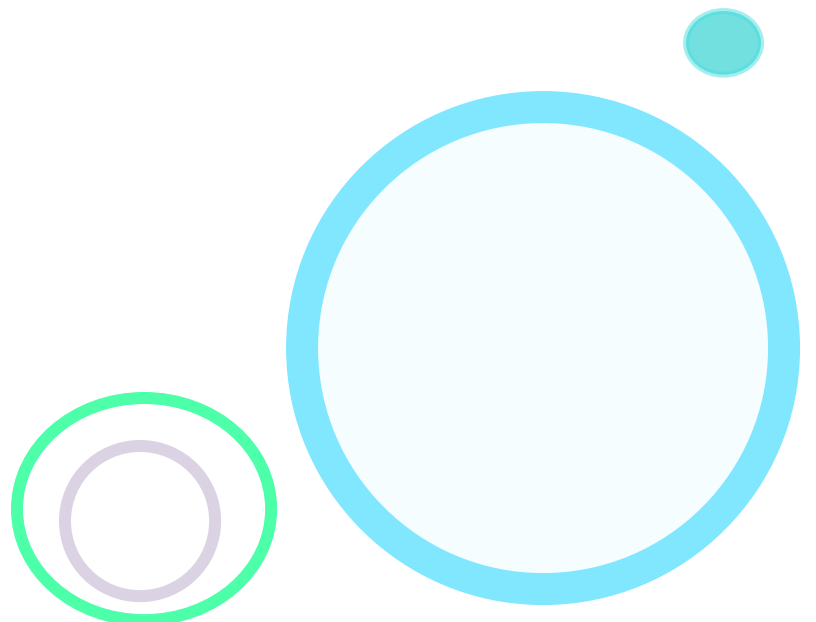
Cardiologist

A Cardiologist is a doctor who knows all about hearts and how they work. They can treat heart problems like murmurs or hearts that skip a beat.



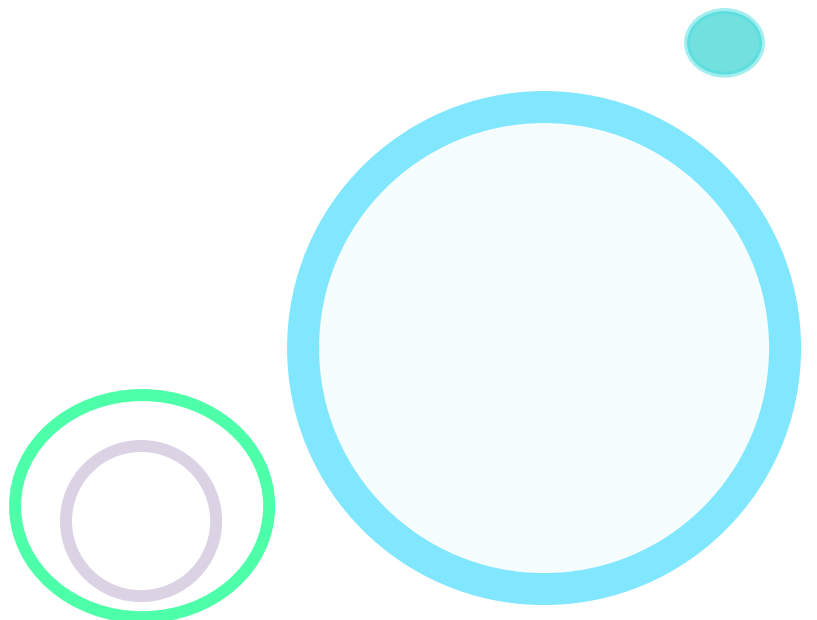
ENT Doctor

An otolaryngologist (ENT doctor) is a doctor who takes care of your ears, nose, and throat. You might go to an ENT doctor if you have too many ear infections or have problems with your tonsils.



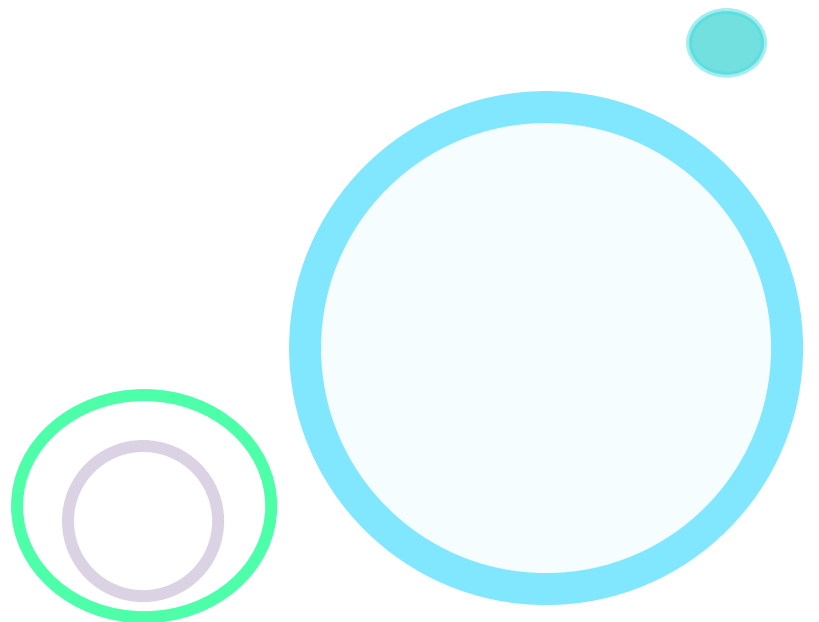
Ophthalmologist

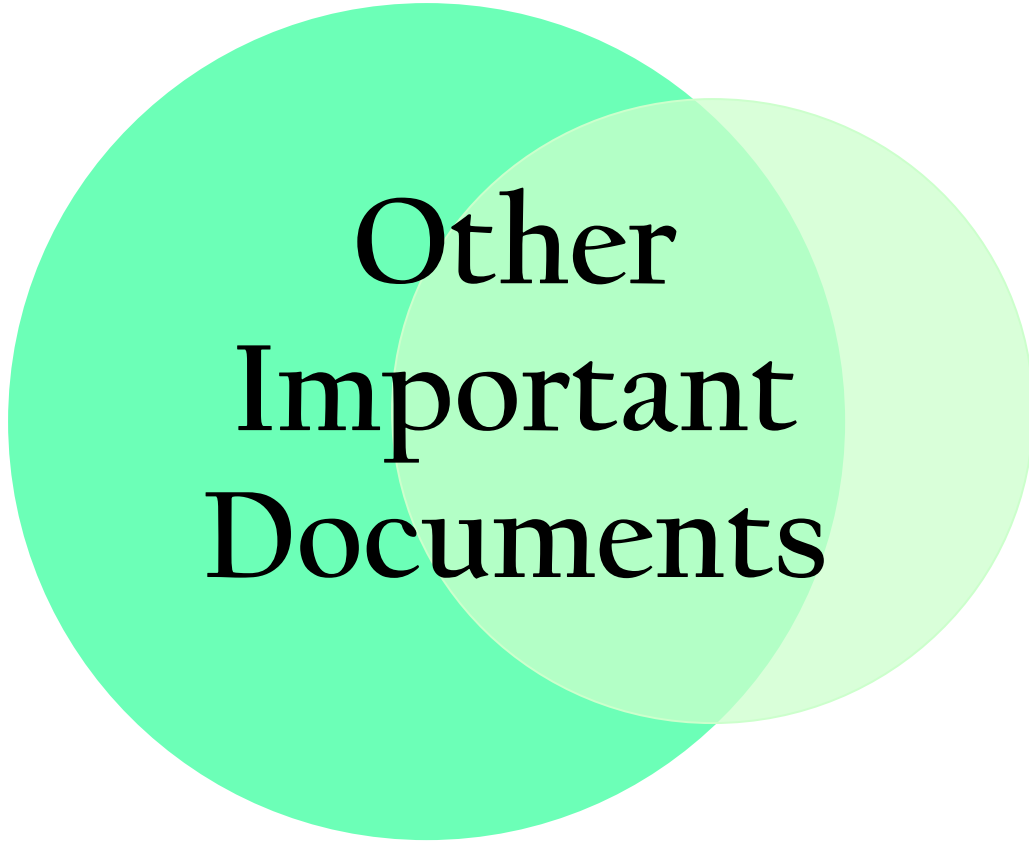
An Ophthalmologist is an eye doctor who helps people with all kinds of eye problems so that they can see better and more clearly.



Speech Language Pathologist

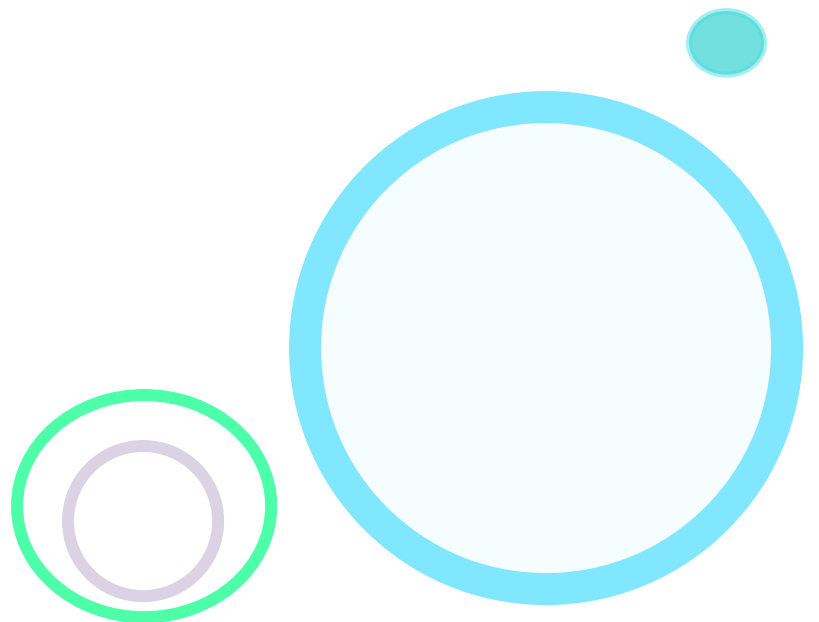
A speech language pathologist is a speech therapist who helps people who have trouble saying certain words or sounds.





Other
Important
Documents

Other Important Healthcare Professionals



Resources – June 2010

- 1) **Medical Expense Credit** is a deduction used when completing Income Tax forms. Various items can be used under the “Medical Expense Credit” as eligible expenses. Some of the items/services include (but not limited to): air conditioners, catheters, cochlear implants, diapers/disposable briefs, eyeglasses, gluten free foods, hearing aids, heart monitors, needles and syringes, and rehabilitative therapy. A family can talk to an accountant, call the Income Tax Information Line @ 1.800.267.6999, or visit the website at www.gc.ca. On the website, click on the A-Z index; follow by clicking on the letter “T”. Scroll down to the “Information for People with Disabilities and click. Click on the second box down from the left. The list provided is not exhaustive.

Federal government funding may be available to assist with the adaptation of a vehicle for a disabled individual. (See the website for further information with regards to individuals with diabetes,

<http://www.diabetes.ca/get-involved/helping-you/advocacy/faq/tax-credit/>)

- 2) **Federal excise gas deduction** – persons medically certified as having permanent mobility impairment and cannot safely use public transportation can apply for a refund of part of the federal excise tax on the gasoline that they purchase. Guardians of Children with behavioural issues who cannot use public transportation can apply for this deduction. Consider children with autism, sensory issues, ADHD, ODD, etc.
- 3) **Federal Child Disability Benefit** - a family can qualify for up to \$2455.00 per year (\$204.58 per month). The eligibility is discussed on the government of Canada website. A qualified practitioner fills completes the appropriate form (T2201) which is the “Disability Tax Credit Certificate”. Qualified practitioners include: medical doctors, optometrists, audiologists, occupational therapists, physiotherapists, psychologists, and speech- language pathologists. If the child qualifies for this credit then they will automatically be eligible for the monthly allowance. The benefit is added to the monthly Child Tax Credit or if applicable, the Child Special Allowance which is also paid on a monthly basis.
- 4) **Alberta Child Health Benefit** for low income families. Provisions may include: eyeglasses, prescription drugs, dental care and diabetic supplies which may include supplies for the insulin pump. The website is www.gov.ab.ca Click on “Programs and Services”, then “Financial Resources”. Scroll down the list and click on the “Alberta Child Health Benefit”.

Physicians, who are prescribing a medication that is not on the Health and Wellness Drug Benefit List, must provide written documentation supporting their rationale for using a drug not listed on the Drug Benefit List. Documentation should also include: the time frame that the child has been taking the drug (A.C.H.B. does

*NOTE: Any request that is made to these programs by a physician is under “Special Authorization”. With regards to a parental benefit plan, the physician can write the company on behalf of the client and request coverage for a medication or supply.

not pay for drugs that a physician is trialling), and a list of other medications used and why these medications were not appropriate. The response time from the ACHB should be in the area of 1-2 weeks. If the application is taking longer than two weeks to process, the family may be reimbursed to a period of before the application was processed.

Prescribed infant formula and special diet items may also be considered for funding with appropriate documentation from a physician. The physicians or parents can contact the A.C.H.B. program at 1.877.469.5437. The physician should have the special authorization form in his or her office however they can also be requested

Alternatively, the family may qualify for the Alberta Adult Health Benefit. The advantage to this program (versus the ACHB) is that the entire family (including the parents) may qualify for coverage. The monthly medical expenses of the entire family will be deducted from the net income. Parents who are interested can contact the AAHB at 1-877-469-5437. In Edmonton call 780-427-6848. Families, who qualify for the Alberta Adult Health Benefit, may receive coverage for items such as formula, diabetic supplies and prescription drugs may be funded.

If a family is not eligible for the AAHB program, they may still be eligible for Alberta Blue Cross Non-Group Coverage premium subsidy. For more information call 780.427.1432 (Edmonton) and 780.310.0000, and enter 780.427.1432 toll free outside of Edmonton.

- 5) **Income Supports, and A.I.S.H.** – the procedure to apply for special authorization above. The physician would address the program and give the reason(s) for the use of the requested drug.
- 6) A list of income **assistance programs** can be viewed at www.servicecanada.gc.ca/eng/subjects/benefits/index.shtml
- 7) **Alberta Food Bank** Network Association's list of food banks across the province is at www.afbna.ca/foodbanks/ or call toll free 1.866.251.2326. The WECAN program is a food co-op that offers nutritious food at low costs. The food co-ops can be found in Sherwood Park, Leduc, Wetaskiwin, St. Albert and Parkland. For more information on WECAN contact them at 780.413.4525 or at www.wecanfood.com
- 8) The **Direct Tenant Subsidy Program** provides a subsidy directly to the tenant to help with high rental costs. The website is www.housing.alberta.ca/direct_to_tenant_rent_supplement_program.cfm
- 9) The **Salvation Army Store locator** provides contact information for Salvation Army outlets across Alberta. The contact number is 1.800.725.2769 or visit the website at www.thriftstore.ca/locations/

- 10) **Alberta Works** offers all Albertans access to emergency accommodation, transportation, and meals when criteria are met. The emergency is service can be accessed through the **Crisis Line** and is available after 4 p.m. During the day, a family can still contact Alberta Works or visit an office for further information. In Edmonton the contact number is 644-5135 (24/7). Outside of Edmonton and across Alberta, the program can be contacted at 1.866.644.5135 (24/7). The operators at Alberta works will ask the caller a number of questions in order to access for eligibility.
- 11) A **Child's Voice Foundation** is a "national not for profit organization dedicated to creating and managing programs that provide tangible help and will make a difference in the lives of financially disadvantaged children in Canada". Their goal is to "support and enhance the physical and emotional well-being of these children by providing products and services not otherwise provided by levels of government, insurance or other organizations". Applicants may be asked for medical verification of a child's condition and income information. Angel Hair for Kids is a part of this organization and may provide a wig for a child with hair loss. For further information and eligibility criteria visit the website at www.achildsvoicefoundation.ca or call the foundation toll free at 1-888-837-3354.
- 12) The **Emergency Repair Program** may provide some funding to low income homeowners and tenants in rural areas for emergency repairs. The website is www.servicecanada.gc.ca/eng/goc/emergency_repair.shtml
- 13) **Benefit Plans** - Parental benefit plans fund many types of services and supports. A benefit person at the place of employment can be contacted with regards to provisions in the benefit plan. As benefit plans change over time, it is imperative that a plan be investigated for potential coverage. There is a process for appeal with most plans. The parent can access this information via a benefits officer at place of employment or by contacting the insurance company or benefit plan.
- Blue Cross province wide for "special authorization" can be contacted at 1.800.661.6995. Other companies providing health coverage can be contacted to learn more about their process for allowances to their plans and the process of requesting authorization.
- 14) A **Guide to Supplementary Health Insurance** is booklet produced by the Canadian Life and Health Insurance Association Inc. This contains information with regards to benefit plans such as, life insurance products and services, company addresses and phone numbers and questions to ask benefit plan agents. There is a toll free number at 1.800.361.8070 (French) or 1.800.268.8099 (English). The website is www.clhio.ca.
- 15) **CHECK OUT YOUR PRIVATE MEDICAL AND LIFE INSURANCE POLICIES FOR COVERAGE OF ADDITIONAL EXPENSES SUCH AS THERAPIES, MEDICAL EQUIPMENT, ASSISTIVE DEVICES, AND TRAVEL COVERAGE.**

Find out if your dependent(s) is/are subject to age limitations, etc. Insurance Bureau of Canada www.ibc.ca

www.finance.alberta.ca/publications/insurance/info_consumer.html lists insurance company websites.

- 16) **Service Clubs, foundations and associations and charities** - Canadian Diabetic Association, Kidney Foundation, Cerebral Palsy Association, and President's Choice, etc.

The **Muscular Dystrophy Association of Canada** has a loan program that may provide basic medical equipment such as scooters, manual and electric wheelchairs and hospital beds. Some funding may be available for the purchase of new equipment.

The **Kidney Foundation** fundraises and gives money to the Stollery (Edmonton) to distribute to families with financial needs. In the south, a renal social worker can fill out requests for equipment and supplies and send them to the Kidney Foundation.

Some programs such as the **Lung Association of Alberta** recycle equipment and make it available to families who meet their eligibility criteria.

The **Residential Access Modification Program (RAMP)** is provincially based and is intended for wheelchair users with a *gross* household income for the prior year of \$35,900 or less. An additional spousal deduction of \$7505.00 is allowed as well as \$7505.00 per dependent child under 21 years and living at home. In addition to this, a deduction of \$6741.00 per disabled child under 18 years and living at home may be made. Call 310-0000, and dial 780-427-5760. The website is www.seniors.gov.ab.ca/AADL/RAMP/

The **Variety Club** at www.varietyclub61.ab.ca/heart_fund.html may assist a family with the purchase of equipment, medical supplies, therapies and assessments, wheelchair lifts, and modifications for accessibility.

The **For the Love of Children Society** at www.fortheloveofchildrensociety.org may assist with treatment, rehabilitation, equipment and supply costs.

The **Children's Ability fund** at www.childrensabilityfund.ab.ca/index.shtml may support families in northern Alberta with the purchase of equipment.

The website, www.wheelchair.ca lists possible funding sources for equipment as well as a list of automotive manufacturers that give rebates for those who must alter their vehicle to accommodate a person with physical disability.

The website, www.oftdf.org is for "**The Opportunities for the Disabled Foundation**". The office can be reached at 1.877.856.3833. This website provides online grant applications for equipment.

Alberta Easter Seals is a program that works with the physically disabled. A caseworker from the Easter Seals Program will review the application and clarify the needs of the individual. The contact number in Edmonton is 780.429.0137 and in Calgary at 403.235.5662.

The **Canadian Cancer Society** (www.cancer.ca) may provide transportation subsidy assistance for travelling to cancer treatment / follow-up appointments. Eligibility is based on household income. Income earners will be asked to provide the most recent "Notice of Assessment" as well as complete an application form. The number of children in the family and parental leave from employment will also be considered in determining eligibility. The Canadian Cancer Society has partnered with Westin Hotels to provide free nights accommodation for patients receiving active cancer treatment in Edmonton or Calgary. The Westin can be contacted at 780.426.3636 (Edmonton) or 403.266.1611 (Calgary). Ask for the accommodations manager.

- 17) The following are a list of **hotels that offer compassionate rates**. Parents may need to provide medical information verifying that they are staying in the city while their child is undergoing medical care or treatment.

EDMONTON:

- Best Western Cedar Park Inn 780-434-7411
- Best Western City Center 780-479-2042
- Coast Edmonton Plaza 780-423-4811
- Econolodge Edmonton 780-438-7979
- Greenwood Inn 780-431-1100
- Ramada Inn and Waterpark 780-434-3431
- Super 8 Hotel South 780-433-8688
- Travelodge Edmonton 780-436-9770
- Ramada Hotel and Conference Centre 780-454-5454

CALGARY

- Best Western Village Park Inn 403-289-0241
- Comfort Inn and Suites South 403-287-7070
- Econolodge Motel Village 403-289-2581
- Holiday Inn McLeod Trail South(Brian) 403-287-2700
- Travelodge 403-289-6600
- Quality Inn University 403-289-1973

- 18) The **Alberta Aids to Daily Living Program** (A.A.D.L.) provides some medical supplies and equipment and is available to all residents of Alberta. The cost share with guardians is A.A.D.L. 75% and the family 25%. The family pays a maximum of \$500.00 per year. The family can apply for Full Benefit Assistance if there are

financial difficulties. An authorizer for A.A.D.L. funding can be accessed at any program that the child may be a part of (Homecare, G.R.I.T., Elves, and Robin Hood). In the case of diapers, the child must be at least three years old with significant delays that have been verified by a professional.

- 19) The **Short Term Equipment Loan Program** (S.T.E.L.P. in the Capital Region) can be reached at 780-413-4990. Medical Equipment Loan Service (M.E.L.S.) in Red Deer at 403-346-1241, Calgary at 403-273-4426, and Grande Prairie at 780-539-7127. This free service is a part of the Red Cross. Items such as wheelchairs, walkers, and bath seats can be borrowed for up to three months. Individuals who have had surgery or are recovering from illness or injury may access this program.

- 20) **Canada Mortgage and Housing Corporation** (CMHC) – The website is www.cmhc.ca/en/inpr/prfias

This website gives information on financial assistance for specific groups of people such as those with disabilities. The program can be contacted at 780-423-8700 (northern Alberta) or 403-515-3000 (southern Alberta).

- 21) www.cadth.ca is a website available to the public to find out the status of a drug that is currently under review. If a child is prescribed a medication that is not listed on the common drug review, the site will give the information as to why the drug has not been included. This may be helpful if a physician is prescribing a medication not on the Drug Benefit List.

The website www.padis.ca is a website that provides information with regards to drug questions, interactions with other drugs, herbal products, as well as tips, and resources. A phone number is listed for individuals if they would like to discuss drug concerns.

The following are websites that provide drug information:

www.genomealberta.ca/tkoolbox.html and www.rxlist.com/. These websites provide links for those who have questions with regards to poisonings, basic drug information and interactions with herbal products.

www.drugcoverage.ca is a website that indicates if any plans exist in a province will potentially cover medication costs.

- 22) **Drug Companies** - A drug company may supply a drug on a compassionate basis as samples to a physician. The physician needs to write a detailed letter to the drug company or talk to a representative of the company and request an ongoing supply for a client.
- 23) The **Alberta Health Services** website at www.albertahealthservices.ca provides information on services across Alberta.

- 24) **Mental Health Link** - 1.877.303.2642. This service offers mental health assessments by registered nurses over the phone. The nurse will assess for symptoms, offer support, and make referrals to resources such as counselling and anger management within the recipient's community.
- 25) www.phac.aspc.gc.ca/chn-rccs/index-eng.php provides health information as well as information on how people can access funding resources for conditions such as diabetes. This information can be accessed under the frequently asked questions (f.a.q.) section at the bottom of the home page.
- 26) www.pwdonline.ca is a website that allows a disabled individual or a guardian of a child with a disability to access assistance in looking for resources that may be able to assist them. The process is done via an on-line survey which will result in a list of provincial and federal resources. On the home page, click on "list of benefits" under "on-line" services. The next step is to choose the province and follow the survey. The result will reveal a list of resources. The home page also lists other items which may have links that are pertinent to families, such as sports programs for the disabled.
- 27) **Interim Federal Health Program (IFH)** offers temporary medical coverage for certain groups of immigrants. The website is www.servicecanada.gc.ca/eng/goc/interim_health.shtml. To access information on emergency dental services call 1-800-770-2998. Information financial loans and assistance can be accessed on this website under "Resettlement Assistance Program".
- 28) The **Calgary Immigrant Aid Society** - "Established in 1977 as the Calgary Immigrant Aid Society, for the past 30 years we have helped over 250,000 immigrants settle into their new life and home in Calgary, Alberta, Canada. As one of Calgary's most comprehensive immigrant serving agencies, our focus is on the individual and families first, providing a sense of community and connection". The society can be reached at info@immigrantservicescalgary.ca or 403.265.1120.
- 29) **Free and reduced fee dental** – Dental services such as examinations, cleaning, sealants, and fillings are done at sites across Alberta. The University of Alberta offers various services from dental hygienists and dental students at the University as well as from satellite clinics in High Level, La Crete, and McLennan. The University of Alberta, Dental Hygiene Program at 780-492-4458 can be contacted for information on low cost and free dental clinics.

N.A.I.T. (Edmonton), S.A.I.T., Columbia College and KDM (Calgary) offer reduced fee cleanings, fluoride treatments and X-rays. The N.A.I.T. Dental Assistance program can be contacted at 780-471-7786. The S.A.I.T. Dental Assistance Program can be reached at 403-284-8380. Columbia College can be reached at 403-235-9314.

KDM can be contacted at 403-264-2744.

Calgary Health Region has community dental clinics for those on limited incomes that do not have dental plans. Families must apply for the reduced fees on cleanings, X-rays, fillings, and removal of teeth.

Calgary Urban Project Society (CUPS) offers limited, free dental services for teeth removal and some fillings for those without dental insurance. They can be contacted at 403-221-8780.

Camrose 780-679-2980, Sedgewick 780-384-3652 and Vegreville 780-632-3331 offer are services such as cleaning, scaling, and fluoride application or children 3-15 without dental insurance. A small fee is charged for these services.

Medicine Hat has a dental clinic through the Community Health Services for those without dental insurance ages 4-12. These services include fluoride, and sealants. The program can be contacted at 403-502-8200.

In Brooks the contact number is 403-501-3300.

Recipients of Income Supports, Alberta Child Health Benefit or the Alberta Adult Health Benefit may be able to have extraordinary dental work covered. Their dentist needs to appeal to the Alberta Dental Service Corporation for funding support for the extraordinary dental procedures.

- 30) The **Oral Maxillofacial Devices and Services Program** may cover some “high cost dental treatments required in conjunction with surgical procedure covered by Alberta Health Care Insurance Plan. For more information (in Edmonton and area) call 780-415-1475. Outside of Edmonton call, 780-310-0000, then 780-415-1475.
- 31) **Eye See...Eye Learn Program** – this program was initiated by the Alberta Association of Optometrists. Children in Kindergarten are eligible to receive free glasses and frames. Parents can find more information by calling their local optometrist or by visiting the website, www.optometrists.ca
- 32) **Child Tax Credit** - As of July 1/07, families can claim a non-refundable tax credit of \$2000.00. This is applicable for all children under 18 years of age. The information can be accessed at www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/Ins360-390/367-eng.html
- 33) **Children’s fitness amount** – A parent may be eligible to claim up to \$500.00 per child for a program of physical activity for their child. Further information is available on line at www.cra-arc.gc.ca/tx/ndvdl/tpcs/ncm-tx/rtrn/cmpltng/ddctns/Ins360-390/365-eng.html
- 34) www.cra-arc.gc.ca/tx/ndvdl/tpcs/rdsp-reei/menu-eng.html provides information on the federal governments’ savings plan for children with a disability. The **Canada Pension Plan (CPP) Disability Benefits** is for Canadians who have

contributed to CPP but cannot work on a regular basis due to a disability. The website is: www.servicecanada.gc.ca/eng/sc/cpp/disability/disabilitypension.shtml

- 35) The Alberta government has fully exempted the federal **RDSP** as income and assets when determining eligibility for provincial financial assistance programs. Government programs affected by this cross-ministry initiative include the Assured Income for the Severely Handicapped (AISH) PROGRAM, the Alberta Seniors Benefit Program, and the Income Support Program. Further information is available at www.rdsp.com.
- 36) **Alberta Blue Cross has a scholarship fund** “for young Albertans pursuing post-secondary studies across the province”. The scholarships are awarded on the basis of “academic achievement and financial need”. For more information visit the Alberta Blue Cross website at www.ab.bluecross.ca/scholars.html
- 37) The **Alberta Scholarship and Bursary program** lists funding that may be accessed by those children with learning/physical disabilities. This website is www.alis.gov.ab.ca/hs/fo/scholarships/scholarships.html
- 38) Information on **savings plans, grants and bonds** for persons with disabilities can be found at www.gc.ca
- 39) The **Mattinson Endowment Fund Scholarship for Disabled Students**, children of some employers and other scholarship information can be found at www.aucc.ca
- 40) The **Canadian Subsidy Directory** contains information on scholarships. The website is www.canadianpublications.net/scholarships/index/htm
- 41) Supports for **military families** such as respite, emergency care, counselling, babysitting and education sessions/programs may be available through their base. Province wide information can be accessed at www.familynavigator.ca/community. The website lists what assistance is available including emergency needs and integration into their communities.
- 42) **Canada Medic Alert Foundation** offers free medic alert bracelets to children across Canada. To find out if a school is participating in this program, check out the website at www.nochildwithout.ca and click on Alberta.
- 43) **The baby department** website offers reduced prices on formula and free shipping for purchases over \$100.00. The website can be accessed at www.Thebabydepartment.com
- 44) The following are reputable websites for **children with autism**: www.autismcentral.ca, and www.cairn-site.com.
- 45) **Edmonton Public Schools** offers a variety of programming to assist students with unique needs (such as cognitive disabilities with significant academic delays,

children with average to high IQ's with learning disabilities. The students must be between five and a half and nineteen years and must meet eligibility criteria. For more information call 780-429-8000 or visit www.epsb.ca.

- 46) **Service Canada** has a website www.jobbank.gc.ca that may provide assistance with finding employment. This website is may be accessed by employers as well as those seeking employment.
- 47) **Nobody's Perfect** is a "parenting education and support program for parents of children from birth to five. It is designed to meet the needs of parents who are young, single, socially or geographically isolated or who have low income or limited formal education". The Public Health Agency of Canada promotes this program. Information can be found at www.phac-aspc.ca/dca-dea/family_famille/nobody-eng.php or call 1-619-952-1220.
- 48) The **Learning Disabilities Association of Canada** – "has provided understanding and support to people with learning disabilities, their parents, teachers and other professionals. Working with our network of provincial/territorial and local partners, we provide cutting edge information on learning disabilities, practical solutions, and tools you can use". The association website is www.ldac-aac.ca/index-e.asp.
- 49) **Compassionate Care Benefits** – " ...these benefits may be paid up to a maximum of 6 weeks to a person who has to be absent from work to provide care or support to a gravely ill family member at risk of dying within 26 weeks." Go to www1.servicecanada.gc.ca/en/ei/types/compassionate_care.shtml.
- 50) The **Hadley School for the Blind** is the largest worldwide distance educator of blind and visually impaired people, their families and blindness service professionals. Founded in 1920 by William Hadley and Dr. E.V.L. Brown, Hadley offers courses free of charge to its blind and visually impaired students and their families and affordable tuition courses to blindness professionals. Today, the school serves more than 10,000 students annually in all 50 states and 100 countries. Hadley relies on contributions from individuals, foundations and corporations to fund its programs. Further information can be accessed at www.hadley.edu.
- 51) **Triple P Parenting- The Positive Parenting Program** is designed to assist parents through each developmental stage by providing seminars, tip sheets and videos. More information is available at www.parentlinkalberta.ca



Education



Business Cards



Contracts



Extra
Copies

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Transitioning Into Adulthood

I am growing up and when I turn 18 I need to start making sure that I have everything in place for adulthood. Here is a checklist of the steps I need to take.



- Have Photo ID
- Get a Social Insurance Number
- Get a Bank Account
- Assemble school and health records
- Establish Guardianship
- Apply for AISH (Assured Income for the Severely Handicapped)
- Apply for PDD (Persons with Developmental Disabilities) Program